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## DOCTOR OF PHILOSOPHY

### Exploring the pathways to poor health in the 'hidden population' with low literacy

Easton, Phyllis

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# Exploring the pathways to poor health in the 'hidden population' with low literacy

Phyllis Easton

2011

University of Dundee

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*Exploring the pathways to  
poor health in the 'hidden  
population' with low literacy*

Phyllis Marguerite Easton

Thesis submitted for the degree of PhD

University of Dundee

September 2011

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To Finlay and Hayley

Without you...

I would have done this in half the time!

But in the words of Elton John:

*"How wonderful life is now you're in the world"*

I, Phyllis Marguerite Easton, hereby certify that this thesis, which is approximately 98,000 words in length, has been written by me. Unless otherwise stated, all references cited have been consulted by me. This is a record of work carried out by me, and it has not been submitted in any previous application for a higher degree.

Date

Signature of candidate

I hereby certify that the candidate has fulfilled the conditions of the Ordinance and Regulations appropriate for the degree of PhD in the University of Dundee and that the candidate is qualified to submit this thesis in application for that degree.

Date

Signature of supervisor

## ***Abstract***

Low literacy remains a problem across the developed world. Health literacy has emerged as a specialist literacy, although its conceptualisation and measurement overlap with those of functional literacy. The social practice view, which conceptualises literacy as an activity rather than a skill, is useful in examining literacy-related practices and demands in healthcare contexts. Associations between low functional or health literacy and poorer health outcomes have been established in the research literature but studies have included participants whose low literacy may be obvious to healthcare providers and others.

This thesis presents first a systematic review that focuses on literacy and health outcomes in the 'hidden population' with low literacy, defined as those of working age whose first language is that of their resident country but who score low on literacy measures. The review concludes that there is a link between low literacy and poorer health in this 'hidden population' but that potential pathways have not been explored to any extent.

The thesis then presents a primary research study which sought to explore links between low literacy and poor health from the perspectives of people with low literacy; and how the health service might respond to address the issues raised. The findings from 25 in-depth interviews and 2 focus groups with adult learners highlighted the various ways that people with low literacy struggle with written and spoken communication in clinical encounters and in self-care activities. They further revealed that stigma frequently plays a central role in the social practices of those with low literacy, affecting their mental wellbeing and social relationships, including those with healthcare staff. The potential solutions identified for service providers would benefit from piloting and evaluation to help create a literacy-sensitive health service, which could improve engagement; enable self-care and enhance capabilities for health in those with low literacy.



# **Chapter 1: Literacy: the problem, concepts and healthcare context**

## ***1.1 Chapter Overview***

This chapter introduces and contextualises literacy as the topic of interest, presenting the existing evidence of associations between low literacy and poor health and highlighting the rationale for the thesis. It begins by describing the nature and size of the problem of low literacy in the developed world. There follows an exploration of the developing concepts of basic and functional literacy and how these are measured. The concept of health literacy is examined and a consideration of the relationships between functional and health literacy concludes that the two concepts overlap and in health research settings, both have been included and/or measured. A general literature review is then presented to describe associations between functional or health literacy and health outcomes, which are well established. Two points in regard to the existing literature are highlighted. The first is that studies have not always controlled for confounding factors and the second, that pathways in the relationships have not been explored to any extent. The existing body of research has sampled from populations whose literacy needs may be obvious and/or different from those who have less obvious literacy difficulties. The notion of a 'hidden population' with low literacy that is not obvious to others is introduced as the population of interest for the remainder of the thesis.

*“Not to be able to read or write or count or communicate is itself a tremendous deprivation. And if the person is thus reduced by illiteracy and innumeracy we can not only see that the person is insecure to whom something terrible could happen, but more immediately, that to him or her something terrible has actually happened”*

Amartya Sen<sup>1</sup>

## **1.2 Introduction**

When Amartya Sen won the Nobel Prize for Economics in 1998, he directed the monetary award into setting up trusts in India and in Bangladesh to research and address illiteracy. This is an issue that has been mainly associated with developing countries, where education is neither compulsory nor available to all. Over the last few decades, there has been a growing recognition that the problem of low literacy is not limited to developing countries but affects industrialised societies also, *“touching even those enjoying a high level of material property.”*<sup>2</sup> Despite economic and social growth, while illiteracy as a complete absence of literacy skills is relatively rare, literacy levels vary considerably within these populations and low literacy continues to be a significant issue across the developed world, and one that has consequences for individuals and societies.

## **1.3 Consequences of low literacy**

It has been claimed that low ‘functional literacy,’ which was defined in the UK as: *“the ability to read, write and speak in English, and to use mathematics at a level necessary to function at work and in society in general”*<sup>3</sup> has economic consequences, and has also been reported as having an impact on the ability of individuals to participate fully in civic society so that they are likely to experience social exclusion.<sup>4</sup> The research literature suggests that there is a relationship between literacy and health and that low literacy may contribute to the health inequalities experienced by some population sub-groups.

### **1.3.1 Economic consequences**

Survey data have suggested that the greater the proportion of adults with low prose literacy skills, the lower a country's gross domestic product (GDP) per capita and conversely the higher the proportion with high prose skills, the higher income per capita.<sup>5</sup> However, there is debate as to whether this is indeed the case and it has been postulated that the economic effect of literacy may be greater at an individual than a societal level.<sup>6</sup> Results from UK survey data have shown individuals with low levels of literacy to be more likely to be: in receipt of government benefits; unemployed; and living in the most deprived areas. Those with low literacy and in employment have been reported as more likely to be in low skill jobs; and on low incomes.<sup>6-8</sup>

Survey data, however, provide only a snapshot of literacy levels and associations and it is unclear how cause and effect relationships might operate. Some of the associations with low literacy may be both causes and effects. For example, people living in the most disadvantaged areas may have low literacy because of lack of opportunity for literacy education or they may be living in such areas because of the employment and income opportunities offered to them due to their low literacy.

One UK study, the British Birth Cohort Study (BCS70)<sup>9</sup> has provided an insight into longitudinal aspects of the association between literacy and socio-economic factors. In the 2004 follow up of the cohort of 16,500, literacy and numeracy skills were assessed using validated questions from the Skills for Life Survey.<sup>7</sup> The BCS70 reported that, at age 34, 39% of men and 36% of women in the survey had literacy abilities at a level *"likely to impact on their employment opportunities and life chances."* It found that those with low skills were less likely to be in full-time work; less likely to have used a computer at work; and less likely to have had work related training than those who performed at a higher level. Those with low skills were also

more likely to be on state benefits and to be part of a non-working household.<sup>9</sup> This cohort study was also able to demonstrate that for those whose skills improved, many of the socio-economic indicators also improved.<sup>9</sup> Such improvement in socio-economic conditions is also linked with reducing social exclusion and promoting social inclusion.

### **1.3.2 Social exclusion**

Social inclusion for individuals has been defined by the European Union as having *“opportunities and resources necessary to participate fully in economic, social and cultural life and to enjoy a standard of living and well-being that is considered normal in the society in which they live”*<sup>10</sup> and it has been proposed that for those with low basic skills (literacy), *“there can hardly be a surer way to social exclusion”*<sup>13</sup> and those with literacy problems have been described as living *“to varying degrees on the fringes of society where writing rules supreme.”*<sup>12</sup>

Education and lifelong learning have been described as central to tackling social exclusion and conversely, promoting social inclusion, mainly through enabling people to participate in the labour market.<sup>11</sup> Other aspects of participation in society were explored in the BCS70, which reported that, as well as experiencing lower participation in the workplace, those with low skills were least likely to vote and most likely to state that they were *“not at all interested in politics.”* Women with low literacy were twice as likely to have been teenage mothers. Physical environment differences were also found between those with low literacy and those with higher literacy. Respondents with low skills were less likely to be homeowners; more likely to live in overcrowded homes; and more likely to report poor local environments,<sup>9</sup> all aspects which may be related to social exclusion through reduced standards of living.

Low levels of literacy have been reported among groups of people who have been formally excluded from participation in society. One UK study reporting the results of formal literacy assessments of prisoners identified 60% as having literacy problems; 40% had severe literacy problems; and 80% had writing skills at or below the level expected of an 11 year old.<sup>12</sup> In another study of a group who may experience social exclusion related to their anti-social behaviour, 25% of young offenders were reported to have reading skills below that of the average 7 year old.<sup>13</sup>

Low literacy has also been associated with aspects of health and healthcare, some of which may in turn be linked to social exclusion.

### ***1.3.3 Associations with individual and societal health***

A high proportion of those with low levels of literacy and numeracy are to be found among people with health problems and disabilities,<sup>6, 8</sup> although a causal relationship cannot be assumed simply from overlapping distributions. Rather, a strong association is suggested between literacy and health and the cause-effect relationship may be two way. For example, work with adults who had sought help with literacy identified health (including mental health) problems as barriers to learning.<sup>14</sup>

Health and well-being differences in terms of health behaviours, self-reported health and mental health and wellbeing have been presented. It has been suggested that people with low literacy are less likely to exercise; more likely to smoke; more than twice as likely to report being in 'poor' or 'very poor' health;<sup>9</sup> and to face health problems in general.<sup>8</sup> Those performing at the lowest levels have also been found to be more likely to report 4 or more symptoms of depression.<sup>9</sup> Social environment differences, which are likely to impact on mental wellbeing have been associated with low literacy. For example, one survey reported that those with low literacy were

less likely to say that they trusted their neighbours or that they felt safe living alone than their cohort counterparts with higher literacy.<sup>9</sup>

Factors that potentially impact on physical health have been linked to low literacy. For example, a significant association between low numeracy skills and higher body mass index (BMI), a risk factor in many major diseases, has been reported.<sup>15</sup> Also related to diet and nutrition, consumer research in the UK revealed that people with basic skills difficulties experienced problems buying food, through inability to read food labels.<sup>16</sup> This has implications for the consumption of a healthy diet, which may in turn lead to obesity or undernutrition (high or low BMI), or in some cases, allergic reaction. The latter study also highlighted issues for the health service, through participant reports that communications from the health service, such as letters from the hospital were difficult to understand.<sup>16</sup>

At a societal level, it has been suggested that life expectancy at birth is higher in countries where a greater proportion of people have high prose literacy.<sup>17</sup> Such inequalities are found within countries as well as at an international level and those, too may be associated with low literacy.

#### ***1.3.4 Contribution to health inequalities***

There is considerable evidence of inequalities in health in the UK<sup>18</sup> and in Scotland,<sup>19</sup> that is, the differences found in health status, experiences of illness and access to health services between different groups in society. These inequalities are most often found between those who are most and least well off and there are known associations between poor health and various socio-economic factors: education; social class; income and living in areas of deprivation, indeed many of the factors which are also associated with low literacy. However, literacy itself is rarely postulated as a risk factor.

Much of the existing work which sets out to explain the socio-economic gradients in health has found that controlling for other known risk factors, such as income, education, or ethnicity, does not eradicate the differentials.<sup>20</sup> This points to other potential factors, one of which may be literacy, and there is epidemiological evidence of health inequalities between those with high literacy skills and those with marginal literacy skills.<sup>21, 22</sup> Sentell and Halpin demonstrated, with data from the 1992 US National Adult Literacy Study, that including adult literacy as a variable reduced the explanatory power of other variables such as race and education in health inequalities.<sup>23</sup>

Literacy difficulties may exacerbate other factors that can contribute to health inequalities. For example, in a US study, 39% of low-income women reading at or below third-grade level did not know the purpose of mammograms for women compared with 12% reading at above ninth-grade level.<sup>24</sup> This was found in the context of low-income women in general making less use of screening mammography; presenting at more advanced stages of disease; and having higher rates of mortality from breast cancer compared with women with higher incomes.<sup>24</sup>

The associations highlighted here are not always clear nor are they mutually exclusive. For example, functional literacy is a correlate of many of the factors associated with poor health such as education and income. However, survey data suggest that those with low literacy, and therefore likely to experience associated consequences, form a considerable proportion of the population.

#### **1.4 The prevalence of low literacy in the UK**

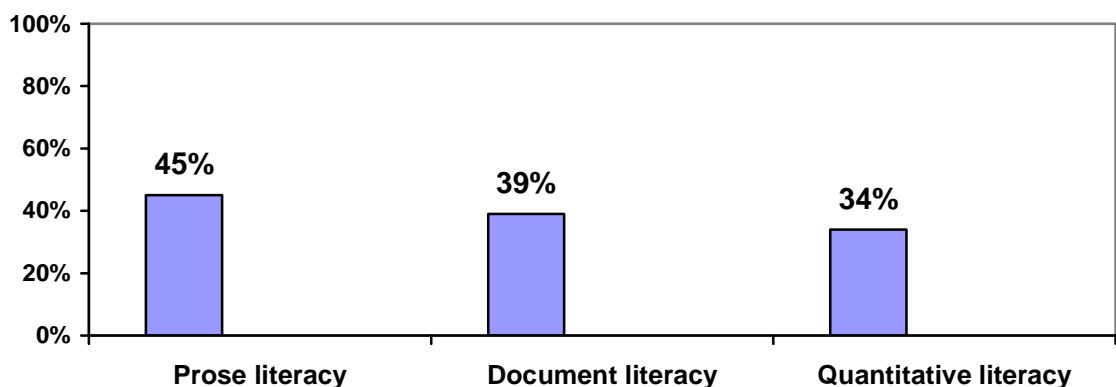
A recent Survey of Adult Literacies, carried out in Scotland, the setting for this study, estimated that three quarters (73.3%) of the population had “*a level of skill that has been recognised internationally as appropriate for a contemporary economy.*”<sup>8</sup> The



report of the survey, which had assessed 1,927 16-65 year olds, suggested that around a quarter (26.7%) may face occasional challenges and constrained opportunities due to their skills but would generally cope with their day to day lives; a small proportion (3.6%) would face serious challenges in their literacy practices.

On further examination, the results demonstrated that a greater proportion than the 26.7% may face challenges. Three domains were included: prose literacy; document literacy; and quantitative literacy and these are explained later in this chapter. Level 3 and above was considered as an indicator that individuals had the literacy skills appropriate for a contemporary economy. However, the 73.3% scoring at the 'recognised skill level' of Level 3 and above applied to *at least one domain*, but not necessarily all three. On examination of the individual literacy domains, the results showed considerable proportions scoring at Level 1 or Level 2 in each i.e. below the level considered to be appropriate for a contemporary economy and therefore likely to face challenges and constrained opportunities in contexts with these particular literacy requirements. (Figure 1)

**Figure 1: Proportion of participants scoring on Level 1 or Level 2:  
Scottish Survey of Adult Literacies 2009**

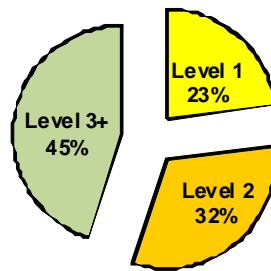


Source: Scottish Survey of Adult Literacies 2009<sup>8</sup>

The Scottish survey was a follow up to the widely quoted 1996 OECD International Adult Literacy Survey (IALS), which included countries within the UK, and used the

same literacy domains and threshold of Level 3 as the point considered to measure adequate literacy. The IALS estimated that 800,000 adults in Scotland, 23% of the adult population, had problems with literacy.<sup>6</sup> The data showed this proportion to be performing at the lowest level of the 5 point scale. A further 32% were found to be performing at Level 2 on the scale, which defined Level 3 as being “a suitable minimum for coping with the demands of everyday life and work in a complex, advanced society.”<sup>6</sup> This suggested that over half the population in Scotland were functioning below the minimum level (Figure 2), a higher rate than the more recent Scottish survey described above.

**Figure 2: Literacy levels of adults in Scotland: Performance on IALS 1996**



Source: *Adult Literacy and Numeracy in Scotland*<sup>6</sup>

Mean scores and distribution of literacy levels were not significantly different from those reported for England, and literacy levels were broadly similar in other parts of the UK and in other developed countries such as the US and Canada.<sup>6</sup> It is unclear if literacy levels in the UK have improved over the period. The lower proportions of people with limited or very limited literacy in the Scottish survey compared with those in previous surveys were reported to be partly due to better survey methodologies.<sup>8</sup>

Although widely quoted, the IALS has been criticised and its validity challenged on a number of counts.<sup>25, 26</sup> One of the main debates over this and subsequent surveys

has focused on the designated literacy levels and their meanings within the analyses. Sticht challenged the construct validity of the IALS, claiming that there was no evidence from studies to support Level 3 as a threshold. He refuted the assertion by the authors of the survey that the level had been set by experts, declaring that there was no record of the said experts.<sup>27</sup> The threshold was defended by the survey statistician, who claimed that proficiency levels were set in accordance with what was expected by employers.<sup>28</sup>

In response, Sticht offered the reported disparity between the measured and perceived levels of literacy among participants as evidence to support his argument, suggesting that people at the lowest levels are able to meet the demands of their jobs and their daily lives.<sup>27</sup> It could be argued that their functioning is, nevertheless, potentially limited and that, while they may have low demands on their literacy in their day to day lives, these limitations are likely to become significant when they are required to meet greater demands through health-related or other unfamiliar social requirements. This is revisited later in the thesis in examining the meaning of functional literacy.

Other areas of debate have been around the definition of literacy used within the IALS, and what was actually measured;<sup>29</sup> and the method of estimating successful responses.<sup>27</sup> Overall, it has been suggested that the IALS results underestimate the literacy levels of participants and have led to continued “*unsupported inferences*” in their use.<sup>27</sup> Subsequent surveys, such as the recent Scottish survey, which have replicated the IALS construct may therefore invite the same criticism.

Regardless of the debate about the significance of particular literacy categories, data from various surveys, across populations in the developed world, have consistently demonstrated widely differing literacy levels. This has been the case however literacy is defined and the suggestion that definitions of functional literacy

in general tend to focus on what is measurable<sup>29</sup> needs to be acknowledged. The changing definitions and concepts suggest that the attainment of adequate functional literacy has required an increasing range of capabilities over time, only some of which are incorporated into the developing measures. The following sections describe and discuss these changing definitions and concepts.

## ***1.5 Changing concepts of literacy***

As long ago as 1922, Bronislaw Malinowski, in his seminal anthropological work with Pacific Trobriand Islanders, provided clear evidence that literacy and language require to be understood in a situational context.<sup>30</sup> Literacy as a social practice, however, was proposed and developed much more recently, in the period since the 1980s, and this is the prevailing view of literacy in Scotland today. Between these two points in time, evolving definitions and concepts of literacy have emerged, in keeping with changes in functional requirements, developing technologies and increasing awareness of the role of literacy in social contexts.

### ***1.5.1 Functional literacy***

The acquisition of technical skills for decoding written texts and producing written statements or, put more simply, as in an early dictionary definition, “*the ability to read and write*,”<sup>31</sup> forms the basis of literacy. Reading, writing and numeracy, are often referred to as basic skills. The skills view of literacy emphasises individual ability and places education firmly in the context of learning to decipher codes and master phonics in order to be able to read the written word. Without basic skills, other aspects of literacy described later may not be fulfilled. Nevertheless, the skills view provides a very narrow perspective that considers literacy independently and does not acknowledge how it is used by individuals or societies.

At this point it is important to note that the use of the term 'illiterate' suggests a division of the population into two groups. Very few people in the UK are completely illiterate. Rather, there is a considerable proportion of the population with less than adequate skills for what is expected of them to function in society.

Functional literacy could be described as basic literacy set *"within the context of everyday life."*<sup>82</sup> An early, and much quoted, definition of functional literacy states *"A person is literate when he has acquired the essential knowledge and skills which enable him to engage in all those activities in which literacy is required for effective functioning in his group and community, and whose attainments in reading, writing and arithmetic make it possible for him to continue to use these skills towards his own and the community's development."*<sup>83</sup> Functional literacy, while taking a skills view, moves into the realm of the literacy requirements of an individual within his society. Literacy is valued for its assumed benefits which include: to enable learning and access to information; to support knowledge acquisition; to develop thinking; and to improve the individual's chances of finding employment and income.<sup>34</sup> Definitions of functional literacy tend to reflect its value to the individual for work related tasks, jobs, employability and the demands of the economy and to the broader society in relation to economic success.<sup>32</sup> This is further confirmed by the accepted role of literacy as an indicator of economic and societal development and the assumed correlation between individual skills and the overall performance of society.<sup>32, 35</sup>

The link between literacy and economic activity was emphasised in the report of a UK Working Group appointed by the Secretary of State for Education and Employment in June 1998 and chaired by Sir Claus Moser. The group, whose main objective was to improve adult basic skills in England, proposed a national strategy, defining functional literacy and numeracy as *"the ability to read, write and speak in English, and to use mathematics at a level necessary to function at work and in*

*society in general*".<sup>3</sup> The limitations for the individual with low literacy skills, in terms of finding employment, or once employed, achieving promotion or change were core issues for the group.

In considering the links between functional literacy and the demands of society, the level required in normal day to day activity is likely to vary according to both social context and content of literacy-related tasks. It could be argued that someone who has low literacy skills but who works in a job that does not require literacy tasks is functionally literate. However, such a job may not be held through personal choice but may rather be one that the person has been required to take because of their low literacy.

*Numeracy* has been included and regarded as a component of literacy in many definitions. Its inclusion in such measures is supported by the proposition that problems with numeracy are not necessarily mathematical or calculation problems, but are related to overall literacy such as finding the layout of a bill difficult, locating the required information to make the calculation or understanding specialised language.<sup>31</sup> Various ways of including numeracy in definitions of literacy have been implemented, including the designation of it as quantitative literacy, as has been the case in several surveys.<sup>8, 36, 37</sup> This and other changes to literacy measures, which reflect the evolving concept of literacy, are described next.

### **1.5.2 Measuring a broadening concept**

Measures of literacy used in large-scale surveys, such as the IALS,<sup>36</sup> have acknowledged the different types of written text that individuals may be required to use and have included them in the assessments. Similarly, formal literacy assessment in the UK has developed into a measure of communication skills, including oral skills, and computing technologies as well as different uses of text for reading, writing and numeracy, as the National Standards demonstrate.<sup>38</sup>

### 1.5.3 Measuring different dimensions

The IALS<sup>36</sup> measured literacy on a continuum for each of the three dimensions of literacy previously introduced: prose; document; and quantitative. The assessment involved the written completion of a booklet covering these three dimensions, which were defined as follows:

- ❑ *Prose literacy*: the knowledge and skills required to understand and use information from text such as newspaper articles and passages of fiction.
- ❑ *Document literacy*: the knowledge and skills required to locate and use information contained in various formats such as timetables, graphs, charts and forms.
- ❑ *Quantitative literacy*: the knowledge and skills required to apply arithmetic operations, either alone or sequentially, to numbers embedded in printed materials, such as calculating savings on items advertised in a sale or working out the interest required to achieve a desired return on an investment.<sup>36</sup>

As already mentioned, results were grouped into five levels where Level 1 was the lowest ability and Level 5 the highest. The survey did not divide participants into literate or illiterate, but Level 3 was defined as being “*a suitable minimum for coping with the demands of everyday life and work in a complex, advanced society.*”<sup>36</sup> The 2009 Scottish Survey used the same three domains and the same levels as the IALS but for the purpose of analysis included Levels 4 and 5 together.<sup>8</sup> Another large scale survey in the US, The Adult Literacy and Life Skills Survey (ALL) added problem solving and information communication technology (ICT) to the three domains.<sup>37</sup>

All three surveys used assessment documents from real-life situations, reflecting a social context and assessing the types of literacy-related activities people might be expected to engage in in day to day life. These included shopping items with prices attached and the need to calculate the price of purchases; a picture of a concert poster asking the respondent to state where the concert was being held; job and house advertisements; charts to be interpreted; posters with sale items; timetables; and forms.<sup>8, 36, 37</sup> The surveys nevertheless relied on written information and did not reflect the wider aspects of communication that are now included in national standard measurements of literacy skills.

#### **1.5.4 National standards**

In the UK, the National Standards For Adult Literacy and Numeracy and ICT provide reference points to different levels of ability. The standards for literacy were designed to specify *“the full range of skills required for an adult to communicate confidently, effectively and efficiently.”* Similarly, they are intended to specify *“the full range of skills required for an adult to confidently apply ICT (or numeracy) skills efficiently and effectively.”*<sup>88</sup> Although these standards match the national curriculum requirements, they are intended for broad use in adult education.

The literacy measures begin at Entry Level 1, which means that adults can *“read and understand short texts with repeated language patterns on familiar topics and can read and obtain information for common signs and symbols.”* At each literacy level, speaking and listening are included as well as reading and writing. Entry Level 1 also requires that adults can *“write to communicate information to an intended audience”* and participate in other communication activities such as *“engage in discussion with another person in a familiar situation about familiar topics,”* thus acknowledging the concept of functional literacy, going beyond the basic skills aspect. There are further Entry Levels 2 and 3, levels expected of a 7



year old and an 11 year old respectively at national curriculum level. Level 1 is the equivalent of GCSE grades D-G and Level 2, the highest level, is the equivalent of GCSE grades A-C, and asserts that adults can *“read and understand a range of texts of varying complexity, accurately and independently and can read and obtain information of varying length and detail from different sources.”* Numeracy and ICT are measured at the same levels, Entry Level 1 through to Level 2.<sup>38</sup>

As well as the broadening understanding of literacy shown by measures which embrace a wider set of skills and contexts, there has also been increasing recognition that literacy is a complex concept. The United Nations Educational, Scientific and Cultural Organization (UNESCO) provided the definition: *“the ability to identify, understand, interpret, create, communicate, compute and use printed and written materials associated with varying contexts. Literacy involves a continuum of learning in enabling individuals to achieve their goals, to develop their knowledge and potential, and to participate fully in their community and wider society”*<sup>39</sup> which reflects and embraces literacy as a dynamic concept. As society changes, so do the demands made in terms of literacy activities in changing social contexts and in the use of emerging technologies so that a static view of literacy becomes inappropriate. The social practice view recognises and accommodates the dynamic concept and varying literacy demands in differing social contexts.

## ***1.6 Literacy as social practice***

The social practice view of literacy was first developed in the 1980s through a body of ethnographic research in a number of communities, known as New Literacy Studies.<sup>35, 40</sup> This view challenged the Great Divide theorists, whose work was set in the context of an assumed gap between oral and written societies and between people who can and cannot read and write. These perspectives fit with the skills view of literacy as an attribute which is given to the individual and can be applied to

different contexts of use.<sup>34</sup> Freire drew an analogy with banking in describing literacy education as something that is deposited into a person.<sup>41</sup>

In contrast, the social practice view describes literacy as something that one does, rather than something one has or is given, and examines how an individual participates in literacy activities in the context of their own everyday life. The social practice view also has an interest in multiple literacies and their different purposes, allowing various media to be included, for example, text messaging, internet and food labels.<sup>34</sup> This differs from the skills view, which considers literacy as a universal set of coding that everyone learns in the same way using standard written texts, with the goal of equipping individuals to deal with universal demands for literacy rather than the context specific nature of literacy.<sup>35</sup>

The perspective of literacy offered by the social practice view is useful in examining the role of literacy in particular social environments. The social basis of literacy can be depicted by people's 'literacy practices,' or how people use reading and writing in a particular situation and 'literacy events' or occasions in everyday life where the written word has a role.<sup>34, 35</sup>

Papen described literacy as a social practice taking place within broader social practices. She used the example of travelling by train to illustrate this. She described the need for literacy and numeracy activities embedded therein, including: buying a rail ticket online, in person, or by phone; calculating ticket prices and timings for the journey; and finding the way to the appropriate platform to catch the train. She also highlighted the social rules and conventions that govern such events and the social participants involved, both institutional (train company, rail company) and individual (traveller, fellow passengers, driver, conductor). Travel agents were also described as 'literacy mediators.'<sup>34</sup> The same scenario could be depicted in a

multitude of social contexts and this is a potentially helpful way of considering wider literacy uses, influences, barriers and potential support systems in these contexts.

The broader conceptual perspective of literacy provided by the social practice view acknowledges that skills and function are linked, so that social contexts are central to literacy and literacy learning. This is reflected in the Scottish Government definition of literacy: *“the ability to read, write and use numbers, to handle information, express ideas and opinions, make decisions and solve problems as family members, workers, citizens and lifelong learners”* a definition intended to emphasise that literacy and numeracy are skills whose sufficiency can only be judged within a specific social, cultural, economic or political context.<sup>6</sup> This moves the concept of literacy into a range of social contexts and Tett combines the skills and function aspects in her interpretation of this definition, which she claims *“shows that to be literate and numerate is not only to have the mechanical skills of encoding and decoding symbols but also the knowledge, skills and understanding that enable us to do what we want to do in our private, family, community and working lives”*<sup>11</sup>

Policy documents in Scotland strongly acknowledge this combination of skills and function in relation to adult literacy and numeracy and take what is now known as a social practice approach to adult learning, so that literacy education takes account of the type of everyday needs it seeks to meet. This is appropriate to the community-based environment of adult education provision in Scotland.<sup>11</sup>

The context of interest in this particular thesis relates to health and the healthcare environment. The social practice view proved to be particularly useful in distinguishing between literacy-related practices, literacy events and the demand made on patients in terms of literacy skills when considering service responses to the issues and potential solutions raised by the primary research.

## ***1.7 Literacy in the healthcare environment – the emerging concept of health literacy***

Within the healthcare environment, literacy and numeracy skills are required to use and understand the considerable amount of written health information relating to health service access, prevention and self-care. There is also a great deal of health information in written form aimed at the general public. While reading skills remain a major requirement, the associated understanding and decisions point to aspects that feature in broader definitions of literacy. In examining the types of activities required, for example, in self-care and in seeking medical treatment, it becomes clear that literacy in the healthcare environment goes far beyond being able to read the relevant information. The example of the social practice of travelling by train, described by Papen,<sup>34</sup> could be transferred to the healthcare environment and applied to examples such as attending a clinical appointment; being admitted to hospital; or implementing self-care in preventive health or self-management of health conditions. Within each of these examples, literacy events take place and the participation in a range of literacy practices and literacy activities may be required.

In the UK, patients accessing any general practice surgery or hospital outpatient clinic will probably be faced with a plethora of posters and leaflets in the waiting areas. They may already have received a letter before their visit, stating the time of the appointment and possibly other instructions such as a request to bring a urine sample. The outcome of the consultation may involve written information being given to the patient, leaflets specific to their diagnosed condition or a prescription which may include detailed instructions, for example, for the use of an inhaler or for dosage and timing of medication. A hospital admission or procedure may have been preceded by a letter with instructions for admission, and possibly other preparatory

requirements, for example, not taking any food beforehand. A consent form may have to be signed on admission and there may be other forms to complete.

Literacy and numeracy activities are performed by many individuals living with long term conditions in order to self-manage their health problems. For example, people with asthma may have to monitor their condition with a peak flow meter, use inhalers, augment therapy with tapering dosages of steroids and avoid triggers that exacerbate their asthma.<sup>42</sup> People with diabetes often need to self-monitor blood glucose, manage multiple medications, visit different healthcare services, maintain foot care, diet, meal plans and exercise<sup>43</sup> The regime for continuing self-care under which hospital inpatients are discharged may also require a complex mix of skills.<sup>44</sup> All of these activities may require the ability to read and comprehend instructions, make calculations and understand the nature of their condition and its management.

Such scenarios have contributed to a recognition generally of the need for a range of functional literacy skills in a healthcare context and this has led to the concept of health literacy which emerged in the 1980s and 1990s, mainly in the US and Canada, and has entered the language of the health service more recently in the UK. There is, as yet, no consensus about what health literacy is and a range of definitions and concepts have been offered, some of which relate more readily to functional literacy and some of which include aspects which fit with the social practice view.

### ***1.8 Definitions and concepts of health literacy***

If we consider that the definition of literacy is often extended to mean to be competent and knowledgeable in specialised areas, such as computer literacy or economic literacy,<sup>35</sup> then health literacy would mean being competent and knowledgeable in the area of health. However, it has been suggested that the term 'health literacy' means different things to different people and that it is a source of

confusion and debate.<sup>45</sup> This would appear to be the case in exploring the multitude of definitions and their interpretation in both the research and policy literature.

### **1.8.1 Health literacy as skills**

Some definitions of health literacy focus narrowly on a functional set of skills. Health literacy fact sheets produced by the US Centre for Health Care Strategies offered the following definition: *“Health literacy is the ability to read, understand and effectively use basic medical instructions and information.”*<sup>21</sup> The definition of the American Medical Association’s Ad Hoc Committee on Health Literacy is more expansive, but, like the previous definition, portrays health literacy as enabling individuals to function as patients and requiring: *“a constellation of skills including the ability to perform basic reading and numerical tasks required to function in the healthcare environment.”*<sup>42</sup>

Such definitions of health literacy refer to skills and present health literacy as a set of individual capacities, which may be improved with education or may decline with age or pathology that impairs cognitive function. It has been suggested that this type of skills definition along with recommendations that health literacy needs to be raised, suggesting that there is a desired level of health literacy to be reached.<sup>45</sup> These views are similar to the skills views of general literacy, portraying health literacy as an attribute and, while acknowledging the social (healthcare) context within which the individual is required to be functionally health literate, they imply universal requirements, rather than variations in social contexts within the overall healthcare setting.

A broader definition, although one that is still focused on skills is offered by the WHO: *“Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.”*<sup>46</sup> This definition

captures additional characteristics determined by these skills, the outcome of which moves away from, but does not necessarily exclude, the ‘individual as patient’ perspective.

Motivation is an interesting component of the WHO definition and one that is not included in any of the definitions of functional literacy. For many people, motivation to gain access to health information in the absence of a particular problem is likely to be low. In particular, those in the most vulnerable groups in society and many people living in poverty may not consider their health or the preventive/maintenance approach to health to be a priority in the face of other complex issues and problems and so may lack the motivation to access health information.

The use of information may also be dependent on other factors albeit many of them associated with low literacy. For example, in the promotion and maintenance of good health, knowing that low fat content is important in purchasing foods and being able to decide from a food label in the supermarket whether a particular item has low fat content may be an aspect of health literacy. Being unable to afford to buy the item may affect how the information is used and this potentially constitutes an element of health literacy that is not dependent on reading or understanding.

Other definitions appear to prescribe particular behaviours, or the need to function in a particular direction.

### **1.8.2 Health literacy as ‘appropriate’ behaviour**

Many definitions, in a similar vein to the WHO, mention the ability to obtain information and go on to suggest that this information is used in a particular way, for example, the definition put forward by the US National Library of Medicine<sup>47</sup> and adopted by Healthy People 2010,<sup>48</sup> which describes health literacy as *“the degree to which individuals have the capacity to obtain, process and understand basic health*

*information and services needed to make appropriate health decisions.*” This implies that health literacy may change behaviour and ultimately improve health. The concepts of “*appropriate health decisions*,”<sup>47, 48</sup> and using information in “*ways which promote and maintain health*”<sup>46</sup> suggest less objective elements of health literacy and the inclusion of not only function but also the requirement to function in a particular direction or way.

Making the right decisions seemed to feature strongly in a conceptual analysis published in 2005, which included, as a defining attribute of health literacy, “*successful functioning as a healthcare consumer*.” In this paper, the health literacy of an 82 year old woman with osteoporosis was demonstrated by her regular discussions with her healthcare provider about her regime and progress with dietary supplements and exercise. Making an informed decision to change behaviour, following the advice of the healthcare provider and keeping the healthcare provider informed were also offered as a demonstration of health literacy. Conversely, an example of inadequate health literacy and therefore failure to function successfully as a healthcare consumer was given in the case of a lawyer who refused to consent to cardiac catheterisation because he did not understand the procedure or the risk posed by his condition.<sup>49</sup>

The example seems unconvincing in that someone with high literacy skills would be unlikely to be unable to understand risk or an explanation of a procedure, and it is interesting that such a patient was not viewed as an example of someone who chose not to take the advice offered. This highlights the issue that acting on information and being able to act on the information are not the same thing and that there exists a perspective that functional health literacy comes with an expectation that behaviour will follow a particular path. There are many examples in everyday life where people have knowledge of health advice but choose not to take it. The smoker who is unaware of the risks and consequences of smoking must be rare in



this age of multiple media warnings of the dangers and while it has been reported that a considerable proportion of smokers would like to quit, many continue to smoke through choice. The role of such knowledge within the context of health literacy is also unclear, however.

### **1.8.3 Health literacy as knowledge**

Health literacy has been described by some directly as knowledge.<sup>22</sup> Others have included knowledge as core to the concept,<sup>50, 51</sup> although what knowledge is required has varied or been unspecified. In the UK, health literacy has been defined in simple terms as *“people’s knowledge and ability to manage their own health”*<sup>22</sup> but knowledge cannot be generic when people’s health and healthcare activities appear in a multitude of contexts. The US Institute of Medicine expert panel divided health literacy into four areas: oral literacy; print literacy; numeracy; and cultural and conceptual knowledge.<sup>52</sup> In this case, cultural and conceptual knowledge resonates with knowledge of social rules and conventions described in the social practice view of literacy.<sup>34</sup>

Pleasant and Kuruvilla provided a perspective which offers a compromise in the debate of where knowledge sits in relation to health literacy. In their paper entitled *‘A tale of two health literacies’*<sup>53</sup> they proposed that, while the clinical encounter is focussed on obtaining information about and from the patient, the public health approach considers the acquisition of health knowledge as an integral part of health literacy rather than a separate outcome.

I would suggest that knowledge as a factor in health literacy is dependent on what the individual is required to do: in a given context; at a given time; at different life stages; and that it varies according to health status. Furthermore, in bringing together the skills and knowledge perspectives of health literacy, there is an

argument as to whether having the knowledge or having the “*capacity*” or “*ability*” to obtain the knowledge is what constitutes health literacy.

Having the knowledge, or obtaining the knowledge, potentially leads to informed decision making although, as already mentioned, having knowledge does not necessarily mean that people will behave in a particular way. This appears to be acknowledged by Berkman et al., who adapted the Healthy People 2010 definition by changing “*appropriate health decisions*” to “*informed health decisions*” pointing out that “*appropriate*” may be misinterpreted to mean that a particular decision is the right one.<sup>54</sup> While it could also be argued that “*informed*” may assume that patients take on the beliefs of their clinical advisors or that the information patients receive may be limited by those holding it, “*informed*” does suggest a more balanced characteristic of decision making than the term “*appropriate*.” This small change potentially provides a different perspective of health literacy and leads to considering its role in enabling people to take more control over their health.

#### **1.8.4 Health literacy as empowerment**

The US Council of State Governments’ Official Guide to Health Literacy stated that “*to be health literate, one must possess the reading, listening, reasoning and problem-solving skills necessary to make informed choices about health and health care.*”<sup>55</sup> This Health Literacy Toolkit thus focused very firmly on informed decision making among patients.

This was clearly the intention of the UK Secretary of State for Health in his foreword to the National Consumer Council report entitled “*Health literacy: being able to make the most of health*” in which the stated aim of addressing health literacy was to help reduce health inequalities and to widen choice “*especially in people that are more socially disadvantaged.*”<sup>22</sup> The Secretary of State for Health went on to state “*An increase in health literacy will increase people’s capacity to take more control*

*over their own health and their own lives.*<sup>22</sup> Health literacy is depicted here as a critical literacy, associated with empowerment of individuals.

The idea of critical literacy was introduced by Paulo Freire, a Brazilian educator, who has had a considerable influence on adult education. His view of literacy moved away from the functional view and presented literacy as something that allows participants to understand the world in terms of justice and injustice, power and oppression.<sup>41</sup> For Freire, literacy was a political concept, which involved learners in critical reflection of the social environment and their own positions and power.<sup>41</sup> Nutbeam described three types of health literacy: functional health literacy, which involves the communication of information; interactive health literacy, which includes the development of personal skills; and critical health literacy.<sup>50</sup> Reminiscent of Freire's concept of critical literacy, there is a strong element of community empowerment in Nutbeam's critical health literacy. The community aspect in both of these is linked to political action.

At an individual level, Nutbeam proposed that higher levels of literacy progressively allow for greater autonomy and personal empowerment and argued that improved health literacy is critical to empowerment, which he advocated as equipping people to overcome structural barriers to health.<sup>50</sup> It may be that if these 'structural barriers to health' described by Nutbeam,<sup>50</sup> and reminiscent of the Social Model of Disability,<sup>56</sup> described later, were removed, improving people's ability to obtain and understand health information could mediate the relationship between low functional literacy and health. Papen provided a community perspective of health literacy that highlighted its potential as a shared resource within communities, including families.<sup>57</sup>

The notion of empowerment, and the steps which can be taken to support it, imply a recognition that literacy is not a static, universal set of skills but an activity that is dynamic and context dependent, as proposed by the social practice view.

### ***1.8.5 Health literacy as a dynamic concept***

Viewing health literacy as a set of static skills is intuitively problematic since health related activities and healthcare do not take place in a static environment or under consistent circumstances. Berkman et al highlighted the notion that health literacy should be viewed as dynamic rather than static<sup>54</sup> and this line of reasoning had been offered previously by Baker, who pointed out that if health literacy includes the ability to function in the healthcare environment, other characteristics of the individual and the healthcare system must come into play. He described health literacy as a dynamic state and suggested that an individual's health literacy could vary depending on the medical problems, the healthcare provider and system.<sup>45</sup>

Zarcadoolas et al. took the dynamic perspective further, describing health literacy as part of a multi-dimensional model and suggesting that an individual who is health literate is able to use health concepts and information generatively i.e. they can apply them to novel situations.<sup>58</sup> The dynamic state concept is in keeping with the social practice view of literacy and the description of literacy events, which have a number of participants and are set in different social contexts.<sup>34</sup>

I would suggest that required literacy practices are likely to vary across different social contexts within the healthcare setting, and also across the life course and according to various health conditions experienced by individuals. Health literacy should be viewed dynamically and as being both content and context specific. I reiterate the argument that whether someone is functionally literate (or functionally health literate) depends on what is required of them. Many real life scenarios illustrate this.

Young people may have very little contact with health services other than for routine screening and minor illnesses treated through primary care. On the other hand, a young person who has been diagnosed with a long-term condition is likely to have a considerable amount of contact with health services, which may include diagnosis; treatment planning; self-care advice; regular checks; and monitoring, at least some of which are likely to take place in an acute care setting. The demands on the young person will increase through all of these stages and the self-care aspect in particular may require knowledge and understanding of the disease and its symptoms; appropriate use of medication and possibly knowledge of environmental factors, which may affect the condition. The potential requirements for functional health literacy in this group are therefore dependent on health status and associated level of clinical or self-care activity.

Health related literacy activities are likely to increase as young people reach adulthood and begin to take care of their own health, including preventive care, and if they become parents, in association with childbirth, infant feeding and future care and treatment of their children. Health problems tend to increase with age, or individuals may become carers for others with health needs and the demands placed on them in terms of health literacy, however it is understood, may also increase. Older people often have complex conditions and co-morbidities, requiring multiple contacts with health services and self-care activities, such as the management of multiple medications and the ability to recognise when to seek medical help.

Health literacy thus appears as a potentially useful concept as a social practice view of literacy with reference to health contexts. The postulated low levels of health literacy in various populations provide snapshots of proportions that may struggle in these contexts.

## ***1.9 The prevalence of low health literacy***

Estimated prevalence of low health literacy varies widely, not least because of the different measures and cutoff points used. In one large scale population survey which specifically measured health literacy, the US National Assessment of Adult Literacy (NAAL), 14% of the 19,000 participants had Below Basic health literacy. This group ranged from being 'nonliterate' to being able to perform tasks which involved locating one piece of information in a simple health text, such as a medical appointment slip, or performing simple numeracy tasks. Twenty two percent of the participants had Basic health literacy, which involved only slightly more difficult tasks within simple texts. Over half (53%) of the total sample were considered to have Intermediate health literacy and 12% Proficient health literacy, the highest level, which involved understanding and analysing complex documents and carrying out multi step numeracy tasks.<sup>59</sup> This survey made comparisons between these groups but did not indicate what would be considered to be adequate health literacy. A sub-group of this large scale study, comprising 6100 parents with children in the household was examined and 28.7% of the parents had Basic or Below Basic health literacy. Over two thirds of parents thus categorised were unable to enter names and birth dates correctly on a health insurance form.<sup>60</sup>

Various studies in the research literature have estimated the prevalence of low health literacy. These focus on particular (mainly clinical) populations and as such, may overestimate the proportion with difficulties in the general population, as clinical groups may be drawn from populations with higher prevalence of other features associated with low literacy. However, it could be argued that it is within clinical populations that health literacy is most important and therefore an appropriate group to test and inform the estimation of the size of the problem.

Focusing on two public hospital populations in the US, Williams et al. reported that 35.1% of English speaking patients were considered to have inadequate or marginal health literacy.<sup>61</sup> In one study from the UK, one in six of the patient population attending a centre for rheumatoid arthritis were described as 'illiterate,' after literacy testing, and it was suggested that they would struggle to cope with patient education materials and prescription labels.<sup>62</sup> Focusing on older people, a cross-sectional survey of 3260 new Medicare enrollees aged 65 or older from four different locations in the US, found that 33.9% of English speaking enrollees had inadequate or marginal health literacy.<sup>63</sup> It was considered that this group may not have the literacy skills necessary to function in the healthcare environment. These studies have also used various instruments and cut-off points to measure functional or health literacy levels, making comparisons difficult.

The prevalence of low health literacy also appears to vary across demographic groups, for example, to increase with age. Within a hospital cohort, it was reported that 81.3% of English speakers aged 60 years and over, the age group which has the highest prevalence of chronic disease, had inadequate or marginal health literacy. This was a significantly higher rate than among younger patients.<sup>61</sup> The difference associated with age may be a cohort effect, or may be due to loss of skills through the ageing process or pathology.<sup>64</sup> The US NAAL found that those aged 65 and over had lower average health literacy than younger participants; that women had higher health literacy than men; and that adults living below the poverty threshold had lower average health literacy than those above the poverty line.<sup>59</sup>

There are clearly similarities between views of health literacy and of functional literacy, and it is important, in examining further the association between literacy or health literacy and health, to establish what the relationship between the two might be.

## ***1.10 Establishing a relationship between functional literacy and health literacy***

The terms 'literacy,' 'health literacy' and 'functional health literacy' appear to be used interchangeably in much of the literature and the variety of definitions and concepts of health literacy offered confirm that there is no real consensus as to what it is. In many of the definitions, there is no clear differentiation between literacy and health literacy except that health literacy is associated with the healthcare environment. Indeed, a considerable proportion of the published papers reporting studies that focus on health literacy begin by describing general literacy levels in the country of interest. The measures of health literacy that are currently available do not assess all aspects of the concept<sup>65</sup> and much of what they do assess could be considered relevant to functional literacy as well. There is potential crossover between the two concepts and in considering many of the assessment instruments used to measure health literacy, functional literacy becomes a prerequisite to health literacy.

### ***1.10.1 Measures of health literacy***

Several measures of health literacy have been developed, mainly in the US and Canada, with some evidence of their use in the UK. While many of the definitions of health literacy include aspects of obtaining and implementing information, and some do not specifically refer to written material, the assessment of health literacy, whichever instrument is used, employs written texts and primarily tests reading skills. Indeed some of the measures of health literacy in the literature are general literacy measures.

Commonly used measures of health literacy in the clinical environment, albeit mainly for research purposes, are the Rapid Estimate of Adult Literacy in Medicine



(REALM)<sup>66</sup> and the Test of Functional Health Literacy in Adults (TOFHLA).<sup>67</sup> These two measures correlate well and have been shown to predict knowledge, behaviours and outcomes<sup>45</sup>. There is also a shortened version of the REALM, the REALM-R<sup>68</sup> and a shortened TOFHLA instrument, known as the S-TOFHLA.<sup>69</sup> The Newest Vital Sign (NVS)<sup>70</sup> was developed to provide a shorter health literacy test that was more appropriate for the clinical environment. A Health Activities Literacy Scale (HALS), not suited to clinical use because of its length, has been used in population survey work.<sup>59</sup> A further two measures, one a revision of the other, have also been used in medical settings. These are the Wide Range Achievement Test (WRAT) and the Wide Range Achievement Test-Revised (WRAT-R), which were designed as general literacy tests and focus on word recognition.<sup>71</sup> Each of these measures is described and discussed briefly below.

Other general literacy measures have been less commonly used in health literacy studies, such as the National Adult Reading Test (NART),<sup>72</sup> Medical Achievement Reading Test (MART)<sup>73</sup> and the Test of Adult Basic Education (TABE).<sup>74</sup>

#### ***1.10.1.1 The Rapid Estimate of Adult Literacy in Medicine (REALM)***

The Rapid Estimate of Adult Literacy in Medicine (REALM) is a word recognition and pronunciation test, which does not test comprehension. It measures on a continuous scale and assigns a reading grade level according to the score but does not measure ability above the 9<sup>th</sup> grade. Although the REALM relies on word recognition, unlike the WRAT, described below, it uses words from a health context, going from list one which contains words such as stress; cancer; and asthma, through list two with words such as notify; miscarriage; and haemorrhoids, to list three, which contains words such as menstrual; inflammatory; and osteoporosis. The REALM takes 2-3 minutes to complete<sup>66</sup> and although it is a reasonably short

test, it contains 66 words. To reduce this, a shorter, eight item version, the REALM-R, was developed.<sup>68</sup>

The REALM score has been identified as a strong predictor of a medication comprehension score and, as such, has been considered potentially appropriate as a screening tool for patients at risk of poor medication comprehension.<sup>75</sup>

#### ***1.10.1.2 The Test of Functional Health Literacy in Adults (TOFHLA)***

The Test of Functional Health Literacy in Adults (TOFHLA) was developed for large-scale, seminal work on health literacy carried out in the US.<sup>61</sup> It uses prompts and a modified Cloze Method to test health literacy. The Cloze method employs a text which has every fifth to seventh word deleted and the respondent is asked to fill in the missing word. The modification for the TOFHLA gives a choice of four possibilities for every deleted word. The TOFHLA provides a score on a continuous scale and a categorical score for three levels: inadequate; marginal; and adequate.<sup>67</sup> The TOFHLA takes 20-25 minutes to complete, which was seen as a disadvantage and this led to the development of the shortened version (S-TOFHLA) which takes 7 minutes to complete.<sup>69</sup>

#### ***1.10.1.3 The Newest Vital Sign (NVS)***

The Newest Vital Sign (NVS) was developed to provide a quick screening test in response to the belief that existing measures were too long for routine use in clinical settings. The NVS, which was developed in English and in Spanish, takes 3 minutes to complete and involves locating information by reading and comprehending, abstract reasoning and numeracy.<sup>70</sup>

This instrument consists of a nutrition label from a carton of ice cream accompanied by six questions testing reading and numeracy skills. Most of the questions require a calculation, for example, *“If you eat the entire container, how many calories will*

*you eat?”* to be worked out from the information that there are 4 servings in the carton and one serving contains 250 calories. The only question that does not require a calculation asks the patient *“Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings. Is it safe for you to eat this ice cream?”* The ice cream label contains peanut oil in the list of ingredients. There is a supplementary question *“Why not?”* if the patient answers *“no”* to the question. Although it was acknowledged that the instrument was composed of mainly quantitative-numerical questions, it has been found to be reliable and to correlate with the TOFHLA.<sup>70</sup>

The NVS has face validity as a test of skills relevant to functioning in a healthcare environment, skills which could apply equally to self-care and preventive action. Baker made the point that instruments should be acceptable to patients and that the NVS, which uses a nutrition label may feel more comfortable and familiar to patients than a list of words.<sup>45</sup>

#### **1.10.1.4 The Health Activities Literacy Scale (HALS)**

The 2003 National Assessment of Adult Literacy in the US, which tested 19,000 adults aged 16 and over, included a section on health literacy specifically, using an instrument known as the Health Activities Literacy Scale (HALS). Results from the health tasks, which were distributed across three domains: clinical, prevention and navigation of the health system, were mapped to the general literacy levels within the overall survey of Basic; Below Basic; Intermediate and Proficient. Health tasks ranged from simply circling the date of a medical appointment on a hospital appointment slip, through identifying a healthy weight range from a BMI graph, to searching through a complex document to find information required to define a medical term.<sup>59</sup> Assessment with the HALS takes approximately one hour to complete, which prohibits its use in a clinical environment.<sup>45</sup>

#### **1.10.1.5 The Wide Range Achievement Test (WRAT-R)**

The Wide Range Achievement Test is a word recognition and pronunciation test which does not test comprehension. It measures on a continuous score and assigns a reading grade level according to the score. The words are not chosen from a healthcare context although it has been used in healthcare. This test takes about 10 minutes to administer.<sup>71</sup> The test, which originated in 1936, has undergone several revisions and the current version (known as the WRAT-R) is widely used for general literacy testing in the US.<sup>76</sup>

#### **1.10.1.6 Health literacy screening questions**

Efforts have been made to find questions from existing measures that correlate closely with the overall results in order to develop shorter more practical instruments for use in a busy clinical environment. One such exercise suggested that one screening question, *“How confident are you filling out medical forms by yourself?”* may be sufficient for detecting limited and marginal health literacy skills in clinic populations.<sup>77</sup> This question, however, may be more appropriate in the US where contact with health services requires more documentation and form completion as well as decisions about medical insurance, than in the UK. Other similar exercises have come up with debatable results and more work is required in this field.<sup>45, 78</sup>

In general, measures do not take into account the dynamic nature of health literacy or the aspects which do not involve reading and writing alone.

#### **1.10.2 Overlapping concepts**

In considering the social basis of literacy, the health literacy screening tests employed would appear to be wanting. While the TOFHLA uses real health documentation, the tests in general measure reading ability rather than health literacy as a broader construct.<sup>50, 71</sup> Tests such as the WRAT-R and the REALM

measure the ability of the patient to recognise and pronounce words in order to assign a reading grade level. It has been pointed out that this may overestimate the ability of the patient to read and comprehend actual passages because correct pronunciation does not necessarily indicate an understanding of the word's meaning.<sup>79, 80</sup>

None of the measures considers the context-specific health literacy needs of the individual. All of them focus on general reading ability, albeit mainly in the healthcare environment. While these will identify patients who are likely to have difficulties with information tasks, they do not acknowledge the wider aspects of health literacy according to the various definitions. The measurement of health literacy thus compares poorly with general literacy testing which now includes other communication skills and ICT.<sup>38</sup> While low functional literacy is very likely to impede the achievement of high health literacy, a person may have high functional literacy but low health literacy. The design of most of the health literacy measures means that people who are functionally literate (or can read well) are likely to achieve high scores even though they may have low health literacy according to the wider definitions given. There would appear to be an overlap between the two concepts that is not necessarily recognised or acknowledged in the literature.

Many of the existing studies fail to differentiate between functional literacy and health literacy. As already mentioned, much of the published research begins with a concept of health literacy but presents data and evidence in relation to functional literacy. However, a distinction between health literacy and general literacy skills, has been described by the US Centre for Health Care Strategies: *“Low health literacy can affect anyone of any age, ethnicity, background, or education level.”*<sup>21</sup> The idea of separate concepts was also borne out by Nielsen-Bohlman et al. who mentioned literacy skills specifically, stating that *“even people with strong literacy skills may have trouble obtaining, understanding and using complex health*

*information.*<sup>62</sup> These highlight the context specific aspect of health literacy which, for many individuals, may be at a lower level than their functional literacy, because unfamiliar vocabulary and ideas may render the healthcare environment more challenging than situations with familiar content.<sup>42</sup>

No matter the literacy skills an individual may have there is the potential to have low literacy in situations where particular expertise and vocabulary are used and the relationship and overlap between functional literacy and health literacy may vary depending on which definitions are considered and which measures are used. People with low health literacy are likely to form a greater proportion of the population than those with low functional literacy. Hahn et al. reported that, among patients with lower reading comprehension, 60% had trouble reading health information, compared with 31% who had trouble reading everyday material and differences were discernible among those with higher reading comprehension also.<sup>81</sup> Using Rothman's model of causal inference,<sup>82</sup> low functional literacy may currently be a sufficient cause of low health literacy, although not a necessary cause. That is, those with low functional literacy will have low health literacy but low health literacy may also apply to people with high functional literacy.

The usefulness of the concept of health literacy may be in helping to examine relevant literacy events and literacy practices in a health and healthcare context. In social practice terms, consultation with a healthcare provider such as a doctor, nurse or pharmacist is a literacy event and some healthcare providers may be viewed as 'health literacy mediators,' particularly in supporting treatment decisions and self-management activities. However, barriers to obtaining information reported by patients include having to ask for information instead of it being offered; health professionals appearing to be pressed for time and not allowing the opportunity for questions to be asked; patients not being given adequate information about treatment and side effects or time to think in advance about what information they

need; and unclear and incomprehensible information being given. This suggests that the role of 'health literacy mediator' is not being fulfilled.<sup>22</sup> The institutional participants in the social practice view may also have a role to play, in this case, the health service or clinical department which sets appointment times and arrangements for consultations which may not be conducive to providing what low-literate patients need in terms of information or support to understand their own health, medication or self-care needs.

These issues may not be unique to people with low literacy, but clearly the dependency on written information for so many aspects of healthcare and self-care will mean that many of these issues are likely to have a greater effect. Viewing health literacy as a social practice may also have much to contribute to the adult basic education curriculum in relation to everyday activities associated with prevention of disease, self-care and in seeking medical help when required.

While many definitions of health literacy are consistent with the notion of literacy as a social practice, the considerable body of relevant research largely neglects such a conceptualisation of health literacy. The design of such research, and estimates of prevalence rates of health literacy rely on a range of what are at best, measures of functional literacy in a healthcare context and at worst, measures of basic reading ability. These considerations lend weight to my conclusion that, as things stand, there is little to differentiate functional and health literacy and that health literacy is better understood as functional literacy related to health and the healthcare system.

The above, perhaps more simplistic view has been offered in the suggestion that patients with the greatest healthcare needs may have the least ability to read and comprehend information needed to function successfully as patients; to navigate the healthcare system; read and understand medication instructions and access other information to support self-care.<sup>42</sup> This echoes the principles of the Inverse Care

Law proposed by Julian Tudor Hart<sup>83</sup> and lends weight to the idea that low literacy may contribute to health inequalities.

There are several issues in relation to literacy in a healthcare context that may contribute to the pathways between low literacy and poorer health as suggested by a considerable body of research literature, summarised next. It should be noted that, because of the overlap in terms and measures, described above, I have considered associations between functional or health literacy, although authors may have referred to one or the other.

### ***1.11 Associations between low functional or health literacy and health***

Research to establish associations between literacy and health and to develop the concept of health literacy has mainly been conducted in the US and Canada and to a lesser extent in Australia.<sup>84, 85</sup> Many studies have found that even after adjusting for confounding variables, such as age, gender, race and socio-economic status, there remain relationships between functional or health literacy and health<sup>43, 44, 75, 86-92</sup> and these relationships are considered to be well established.<sup>93</sup> However, confounding variables are not always controlled for.<sup>71</sup> Some of the most widely quoted papers from the considerable body of research on the subject, which includes evidence of associations between health literacy and health status; use of health services; knowledge and management of chronic conditions and adherence to treatment, are summarised in this initial broad literature review. The published studies are mainly cross-sectional in nature; use various measures; and do not explore longitudinal aspects of functional or health literacy and the outcomes of interest. It is unclear which of the findings are transferable to the UK, or to Scotland in particular and also, little is known about the pathways between low literacy (including health literacy) and poorer health.



### **1.11.1 Health status**

Low health literacy has been strongly associated with poorer health status, both self-reported and objectively measured, and with mortality. In the general population, the 2003 National Assessment of Adult Literacy in the US found that, at every increasing level of self-reported health, adults had higher average health literacy than those in the level below.<sup>59</sup> Results from a large-scale cross-sectional study in two urban public hospitals in Atlanta, Georgia and in Torrance, California showed that patients with inadequate health literacy were more likely to report their health as poor.<sup>87</sup> This association was also found in Arizona, with a sample of adults undertaking literacy training. Those with extremely low reading levels reported their physical health to be poorer than those with higher reading levels, even after adjusting for confounding socio-demographic variables. The relationship between reading level and psychosocial health was also presented as statistically significant after adjusting for confounding variables.<sup>91</sup> In community residents, low health literacy in an older population was independently associated with poorer physical function and poorer mental health as measured by standard health and function instruments.<sup>90</sup> Limited health literacy has also been associated with an almost twofold increase in mortality in an elderly population.<sup>94</sup>

### **1.11.2 Access to health services**

It has been reported that patients with low health literacy tend to use health services differently compared with patients with higher health literacy. This may be related to engagement with service procedures, particularly when written information needs to be understood and implemented. In a US study, Williams et al. found that 26% of 1892 English speaking patients could not understand information about their next appointment and 59.5% could not understand a standard informed consent document.<sup>95</sup> Other US studies have found associations between low health literacy

and outcomes such as higher risk of hospital admission;<sup>44, 87, 96</sup> and higher number of non-emergency visits to their doctor over a two year period although in this particular study, no difference was found in emergency department use according to reading ability<sup>44</sup> This did not agree with the findings of other US studies, where lower literacy has been associated with higher emergency department use.<sup>52, 97</sup> One of the studies which reported higher emergency department use found no relationship between health literacy and regular source of care or physician visits, and the authors concluded that low reading skill does not reduce access to care, and under-use of healthcare services does not explain differences in health.<sup>97</sup> In Glasgow, Scotland, patients with rheumatoid arthritis and low literacy had significantly more hospital visits than those with adequate literacy, even though they had similar functional abilities and disease histories.<sup>62</sup> It has been suggested, however, that low-literate patients may use fewer services than they need.<sup>87</sup> This leads to a question about *appropriate* use and whether increased contact with services is appropriate or not.

### **1.11.3 Self-management of health problems**

Knowledge and management of chronic conditions has also been associated with health literacy level. A survey of 402 patients with hypertension revealed that knowledge of their condition was strongly related to their health literacy score.<sup>89</sup> The same authors also found that patients with low health literacy, had lower levels of diabetes-related knowledge and were less likely to interpret or act on their diabetes monitoring.<sup>89</sup> Similar findings have been reported by others: patients with type 2 diabetes who had inadequate health literacy have been reported to be less likely than patients with adequate health literacy to achieve tight glycemic control; to be more likely to have poor glycemic control and to report having retinopathy.<sup>43</sup> Other conditions have been examined with findings suggesting similar associations. For example, in a cross-sectional survey of 273 patients in Atlanta, Georgia, patient

reading level was the strongest predictor of asthma knowledge and of metered dose inhaler technique.<sup>89</sup> Inadequate literacy has been strongly correlated with both poorer knowledge and improper inhaler use;<sup>89</sup> worse quality of life, worse physical function and higher emergency department use for asthma.<sup>98</sup> Potential consequences of low health literacy were reported by Bennett et al who suggested that it may be an unrecognised barrier to early diagnosis of prostate cancer due to late presentation associated with low patient awareness of prostate cancer.<sup>99</sup>

One study, which reported that lower health literacy was associated with poor longitudinal asthma outcomes also suggested that health literacy may affect outcomes by impeding the acquisition of asthma knowledge, including knowledge of asthma related vocabulary.<sup>98</sup> Other examples of correlations between health literacy and knowledge have been described.<sup>24, 88, 89, 100</sup> These studies, however, do not answer the question of whether knowledge is a result of health literacy or a component of it and there may be confusion as to which is relevant.

Adherence to prescribed medication is an area where health literacy has been recognised as having an important role and patients have reported serious medication errors resulting from their inability to read labels.<sup>101</sup> Williams et al. in their US large scale urban hospital study found that 41.6% of patients were unable to understand instructions for taking medication on an empty stomach.<sup>61</sup> In structured interviews with 251 patients whose literacy had been assessed, comprehension of drug warning labels, such as *“do not chew or crush, swallow whole”* or *“for external use only”* was associated with literacy level, those with low literacy demonstrating poorer comprehension.<sup>102</sup> It was also found that, although patients at all literacy levels had a greater understanding of single-step rather than multi-step instructions, those with low health literacy were 3.4 times less likely to interpret prescription medication warning labels correctly.<sup>102</sup> This is a safety issue as well as an issue for appropriate and correct use of medication. It has been described as *“unintentional*

*nonadherence*” and may be an unrecognised contributor to hospital admissions caused by misuse of prescription medicines.<sup>102</sup> Other studies have found no association between health literacy and self-reported adherence with warfarin;<sup>100</sup> with antiretroviral therapy or virological suppression in HIV patients;<sup>103</sup> or with warfarin control in anticoagulated patients.<sup>100</sup>

#### **1.11.4 Comparison of studies**

Studies used various measures and cut-off points, making it difficult to compare levels of health literacy and relationships with health outcomes across studies. Wolf et al. reviewed existing data to examine whether there was a threshold below which literacy was independently associated with health or whether the relationship was continuous across the literacy spectrum. They concluded that although there was some evidence of a threshold effect in particular studies, the nature of the relationship varied depending on the outcome under examination.<sup>104</sup> This contributes to the argument that health literacy is not a generic stand alone set of skills, but a dynamic, context dependent activity.

Other features of the existing research suggest that the findings are not necessarily applicable to other populations, particularly in the UK. Differences in the healthcare systems in the countries where most of the health literacy research has been carried out may affect the transferability of the findings to UK patient and community populations, particularly in considering costs of healthcare and how these are met, the role of seeking and implementing health insurance and differences in the ways patients access services. In addition, while there is a considerable amount of evidence in the literature of the association between functional or health literacy and various aspects of health, it is unclear how much of the association is due to confounding, since there are associations between literacy and many other factors

associated with poor health, such as education, socio-economic factors, self-efficacy and demographic factors.

### ***1.11.5 Confounding variables in the relationships between functional or health literacy and health***

#### ***1.11.5.1 Years of education***

Number of years of education is often used as a measure of literacy but as Baker points out, they measure how long people have been in school, not what they achieved while they were there.<sup>44</sup> The US Education Department National Adult Literacy Survey found that approximately a quarter of those scoring the lowest of 5 literacy levels were high school graduates.<sup>105</sup>

There is considerable evidence in the literature to suggest that although there are correlations between length of time in education and literacy, the two do not necessarily match as expected<sup>6, 59, 106</sup> and one study highlighted that patient reports of number of years of school completed was four or five levels higher than their reading ability.<sup>107</sup> Similarly, in a study of low-income women and their knowledge of screening mammography, it was reported that the functional literacy of participants was considerably lower than their educational level suggested.<sup>24</sup>

In the UK, educational attainment was the most important explanatory variable in literacy performance in the International Adult Literacy Survey. However, it explained only 29% of the variance.<sup>6</sup>

#### ***1.11.5.2 Demographic and socio-economic factors***

Various demographic and socio-economic factors may be associated with both literacy and health. It has been suggested that most of the association between literacy and health is probably related to difficulties getting and maintaining a job, leading to impoverishment and associated health risks.<sup>87</sup> It was reported that in one

elderly population, health literacy explained some of the differences in health status and to a lesser degree, receipt of vaccinations, normally attributed to race or education.<sup>108</sup> However, in an elderly population in particular, lower literacy may be a consequence of ill health as well as a cause.

It was established from one systematic review in 2004, that existing research did not address confounding variables.<sup>71</sup>

As already mentioned, many of the studies conducted to establish a relationship between literacy and health have sampled from populations whose literacy difficulties may be more likely to be recognised and addressed by health services and staff such as minority ethnic or elderly populations. Relatively little is known about the implications of low functional or health literacy among people whose literacy difficulties are, for a number of reasons described in the next chapter, more likely to be hidden from healthcare staff and others. This 'hidden population' is the population of interest in the remainder of this thesis.

### ***1.12 Conclusion to this chapter***

Low literacy is a significant problem across the developed world and the emerging concept of health literacy is prominent in the research literature. The social practice view provides a useful approach in considering the wider aspects of health literacy although these are neither measured nor examined in the existing literature. While there is evidence of an association between functional or health literacy and health, many different measures, populations and health outcomes have been included. The proliferation of confounding variables, which have not always been controlled for, suggest that there is still debate around the strength of associations. Nevertheless, it is considered that there is a well established relationship between low literacy and poorer health.

From a health service perspective it would also be useful to examine which pathways are evidenced in the relationship between literacy and health and which of these could be addressed through the health service. This is of particular interest in the population with low literacy that is more likely to be hidden from healthcare staff and others. Examining these pathways and establishing which are most important in supporting people with low literacy skills to access and benefit from health services, could be the first steps towards mediating the effects of low literacy on health.

## **Chapter 2: What evidence is there of an association between low literacy and poor health in the ‘hidden population’?**

### ***2.1 Chapter Overview***

In this chapter, the concept of the ‘hidden population’ whose literacy problems may not be obvious to healthcare staff and others is described. There follows a systematic review of the literature which focuses on literacy and health in a working age population whose first language is that of their resident country. The chapter concludes that there is a link between low literacy and poorer health in this ‘hidden population’ but that potential pathways have not been explored to any extent.



*“Literacy is a bridge from misery to hope.....Especially for girls and women, it is an agent of family health and nutrition.”*

Kofi Annan, International Literacy Day, 8 September 1997

## ***2.2 Introduction***

In the previous chapter, various perspectives and concepts of literacy were presented and literacy in a healthcare context was discussed. An overview of what are considered to be well established associations between functional or health literacy and various health outcomes followed. Two issues were not evident from a general literature review: potential pathways between functional or health literacy and health outcomes; and whether the associations that have been demonstrated in the research literature apply to the population whose low literacy is more hidden. I begin by describing what I have termed the ‘hidden population’ and the rationale for my particular interest in this group.

## ***2.3 The case for the existence of a ‘hidden population’***

There are several reasons why an individual may either reach adulthood or become an adult with less than adequate functional literacy. The low literacy of an individual may be more or less obvious to others, such as healthcare staff, depending on which of these reasons has contributed to the problem. Low literacy may be associated with learning disabilities; cognitive impairment, including that due to ageing; or pathology. People may also have difficulty with literacy activities because their first language is not the dominant language of the country or setting for these activities. Other reasons for adults to have low literacy include suboptimal education and dyslexia, sometimes undiagnosed. Other factors that contribute to the existence and the maintenance of a hidden population, include: people’s own lack of recognition of their literacy difficulties; non-disclosure of literacy problems often due to shame and stigma; low awareness among healthcare staff of potential low literacy in patients; and the coping strategies employed by those with low literacy.

### **2.3.1 Learning disabilities**

Learning disability has been described as “a significant, lifelong condition that started before adulthood, that affects the individual’s development and means they need help to understand information, learn new skills and cope independently”<sup>109</sup>

More specifically, learning disabilities are associated with characteristics such as: a significant impairment of intelligence; a significant impairment of adaptive functioning; and the age of onset occurs before adulthood (in other words, in the developmental period).<sup>110</sup> People with learning disabilities may therefore have difficulties reading, understanding written information, performing numeracy activities and setting information in a particular context such as healthcare or self-care.

### **2.3.2 Cognitive or sensory impairment**

Cognitive or sensory impairment may be associated with a congenital condition or may be acquired over the life course, most commonly through ageing. Health professionals may be more likely to consider the possibility of low literacy among older than younger adults if they associate ageing with visual and/or cognitive impairments. They may also believe in general that older cohorts were more likely to have missed out on schooling as children. Cognitive impairment may also occur because of pathology, such as when someone has suffered a stroke, has diagnosed dementia, or has experienced brain or head trauma, resulting in the loss or reduction of literacy skills. Sensory impairment, such as visual loss may also be associated with both of these groups, for whom their low literacy is potentially obvious to those in close contact with them such as in a healthcare consultation. Healthcare staff may be more likely to give clear or increased oral instruction to people whom they believe to have learning disabilities or to suffer cognitive or sensory impairment, although this should not be assumed to be the case.

### ***2.3.3 Language not literacy***

People may have difficulty with literacy activities if they do not speak, or speak as an additional language, the dominant language of their resident country or social setting, such as the healthcare environment. However, they may be highly literate in their first language. It will be evident in healthcare consultations that people from minority ethnic groups who do not speak the dominant language of their country of residence or health service may struggle in that context unless alternative language provision is made. When literacy difficulties are associated with language differences, they may be addressed through interpretation and translation.

Some people have less obvious literacy difficulties and these include people with low literacy linked to suboptimal education or dyslexia or both.

### ***2.3.4 Suboptimal education***

In the UK, where formal education is compulsory between the ages of 5 and 16, schooling can nevertheless be disrupted or missed. Frequent changes of school, due to families moving home or travelling, can lead to lack of continuity in education and difficulties integrating into different schools and classes. Young people may truant frequently and this is sometimes encouraged by parents when they are kept off school to look after younger siblings or to help in the home. Childhood illness may also be a cause of periods of missed education. All of these may coincide with children missing crucial stages of literacy learning and being unable to catch up once they have fallen behind. Suboptimal education may be the cause of literacy difficulties for some, while for others their low literacy may be caused by dyslexia.

### ***2.3.5 Dyslexia***

Dyslexia is generally considered to be a hereditary neurological condition with educational implications. The medical discourse associated with dyslexia is

supported by brain imaging studies and post-mortem examinations which have highlighted differences in the brains of dyslexic and non-dyslexic individuals, specifically in regions of the brain associated with reading, language and phonological processing. Differences in visual pathways and a strong genetic basis have also been linked with dyslexia.<sup>111</sup> The educational discourse is concerned with dyslexia as resulting from learning dysfunction and conceptualises it as a specific learning difficulty where symptoms are overcome by educational adjustment or accommodation. How dyslexia is defined may therefore depend on the lens through which it is viewed.

A working definition of dyslexia was agreed by the Scottish Government, Dyslexia Scotland and a Cross Party Group on Dyslexia in 2009:

*"Dyslexia can be described as a continuum of difficulties in learning to read, write and/or spell, which persist despite the provision of appropriate learning opportunities. These difficulties often do not reflect an individual's cognitive abilities and may not be typical of performance in other areas."*<sup>112</sup>

As the above definition highlights, dyslexia is a continuum, and it can affect individuals in various ways as well as to varying degrees. Dyslexia may be associated with difficulties such as: auditory and /or visual processing of language-based information; phonological awareness; oral language skills and reading fluency; short-term and working memory; sequencing and directionality; number skills; and organisational ability.<sup>112</sup> When reading and spelling difficulties cannot be explained by other factors, an assessment for and diagnosis of dyslexia may be made.<sup>111</sup> While many people have been diagnosed as having dyslexia, recognition and assessment through the education system has been a relatively recent practice and testing for possible dyslexia does not happen automatically when pupils struggle with literacy activities. There is therefore a considerable number of people

who have undiagnosed dyslexia, across all age groups, but particularly among those who had their formal education some time ago, when dyslexia was not recognised by schools, parents or individuals as a potential reason for literacy difficulties.

The latter two groups, those who have experienced suboptimal education and those with dyslexia are not only less visible but for a number of reasons, presented next, may not disclose their low literacy to others such as healthcare staff.

### ***2.3.6 People's perceptions of their own literacy skills***

Low literacy may not be recognised by individuals themselves and this has been suggested by survey results.<sup>5, 9</sup> The 2001 report on adult literacy and numeracy in Scotland<sup>6</sup> emphasised that those with low levels of skills are not a homogeneous group but one that contains individuals with a range of skill levels including being unable to read at all; having some difficulties; and needing to brush up on their skills. It also highlighted that a considerable proportion of people with low literacy either do not reveal the problem or are unaware of it. In comparison with the estimated 23% of the population with very low literacy, only 7% of participants reported needing help with writing notes or letters and 5% reported needing help with basic arithmetic.<sup>6</sup>

The suggestion that some people who have low literacy skills do not recognise it and do not seek help was also put forward in the 2002 Basic Skills and Social Exclusion Report, which was part of the BCS70.<sup>86</sup> The majority of participants considered to have low literacy skills in American adult surveys also described themselves as being able to read and write English well or very well.<sup>42, 105</sup> This discrepancy between actual and perceived literacy levels may be explained in part by the different demands made on people and the fact that many people with low skills learn to cope with them and manage very well day to day.<sup>9</sup> For those who do

not need to read very often, their lack of ability may only become apparent when the demand for them to read something they do not understand occurs.<sup>101</sup> Nevertheless, they add to the hidden population who do not identify themselves as such, and even if they recognise their limited literacy skills, they may not disclose them to others.

### ***2.3.7 Shame and stigma associated with low literacy***

Low literacy, however it is defined, emphasises a deficit in skills as a problem that raises a need for education. This view is taken further when illiteracy is referred to as something to be eradicated, as it has commonly appeared in the media and in public discussion. Newspaper headlines have referred to an “*epidemic of illiteracy*” and this disease metaphor has, on occasion been expanded to include the idea of literacy as an inoculation against negative influences.<sup>35</sup> In a study with parents to establish perspectives of literacy, it was found that literacy can be associated with morality and with being good or bad.<sup>113</sup> Other characteristics linked with illiteracy include criminality; not being able to get a job; and being a burden on the economy,<sup>35</sup> all negative associations potentially contributing to shame and stigma.

Shame and stigma may prevent a considerable proportion of the population with low literacy from revealing their difficulties to others. Work in Atlanta, Georgia with patients who admitted to the researchers to having trouble reading, found that almost two thirds (67.2%) had never told their spouses, and over half (53.4%) had never told their children of their difficulties reading. Almost one in five (19%) patients had never disclosed their low literacy to anyone.<sup>114</sup> Healthcare staff may also be unaware of the potential for literacy problems among their patients.

### ***2.3.8 Low awareness among healthcare staff of potential low literacy***

There is evidence that many healthcare professionals are unaware of patients' difficulties with reading or numeracy<sup>115</sup> or overestimate the literacy abilities of their patients.<sup>64</sup> One study established that thirty six per cent of the patients that resident physicians regarded as having no literacy problems could not read six out of eight common medical words.<sup>116</sup> Working age adults who can engage in spoken conversations in the dominant language are potentially most able to keep their low literacy hidden as their ability to speak the dominant language well and to communicate orally can mask it. In addition, a literacy problem may not be evident to the healthcare provider if literacy activities are not part of the consultation.

If healthcare staff do not recognise low literacy, they are unlikely to acknowledge a possible need for oral explanation or otherwise make allowances. Results of an analysis of audio tapes of doctor-patient encounters in Portland Oregon to examine clinical decision-making processes, showed that the physicians assessed patient understanding only 1.5% of the time. There was also wide variation in how much was explained to inform the decision.<sup>117</sup> This was borne out in a qualitative study examining patient involvement in treatment decisions when participants stated that they had received, or taken in, very little information at first diagnosis.<sup>118</sup> These issues may not be unique to patients with literacy problems but as a group, they will have less potential to compensate for the lack of information or understanding at the time of consultation because of difficulties accessing other sources. However, people with low literacy employ a range of coping strategies to help access health services and deal with health issues.

### ***2.3.9 Coping strategies implemented by people with low literacy***

Several coping strategies in accessing health services have been reported. One such strategy is to have family members or friends serve as surrogate readers.<sup>101</sup>



However, this requires that surrogate readers are aware of the literacy problem and there is evidence that a considerable proportion of people who struggle with reading have not disclosed this to their family or friends.<sup>114</sup> People who have kept their difficulties hidden will not have this option open and will not be able to seek help on their return home, unless by subterfuge. Other coping strategies, such as claiming to have forgotten reading glasses are implemented to avoid disclosure of low literacy in clinical consultation. These nevertheless have the potential to mislead healthcare staff and to maintain their lack of awareness. Coping strategies may thus help hide the problem from healthcare providers and others who may be able to help and so in themselves can lead to missed opportunities to obtain health information and advice.

There are thus many factors that contribute to a hidden population with low literacy. My main interest was to explore the implications of low functional or health literacy among the hidden population, which was defined for the purpose of this research as people of working age whose first language was English and who had no obvious literacy difficulties. The hidden population excludes the groups that were described above as potentially being more visible to healthcare staff and others. It should be noted, however, that this is not a clear and fixed population. It is possible that individuals with literacy difficulties may be hidden in some contexts and not in others and this may include some but not all healthcare contexts. To my knowledge, this population had not been the primary focus of existing research.

I began by carrying out a systematic review to help further understand the relationship between functional or health literacy level and health in a working age population whose low functional or health literacy may be neither obvious nor readily identifiable to healthcare staff and others.

## **2.4 Systematic review**

### **2.4.1 Aim**

The review sought to establish evidence of associations between low functional or health literacy and health in a working age population whose first language was the dominant language of their country.

### **2.4.2 Review questions**

The review questions were, for the population of interest:

1. What evidence is there of an association between functional or health literacy level and health status?
2. What evidence is there of an association between functional or health literacy level and the following potential mediating variables:
  - ❑ health promoting or health risk behaviours?
  - ❑ access to and use of health services?
  - ❑ self-management of health problems?
3. Is there evidence that knowledge of particular health risk or health conditions may mediate the relationship between functional or health literacy and health behaviours?

### **2.4.3 Methods**

#### **2.4.3.1 Inclusion Criteria**

I considered studies of any design which examined relationships between functional or health literacy and health outcomes or health-related knowledge or behaviours in a working age population whose first language was the dominant language of their resident country. Only studies which had assessed literacy with a validated measure or had included participants who were attending an adult literacy programme were included. A full list of inclusion and exclusion criteria is shown in Table 1.

#### **2.4.3.2 Search strategies**

I searched for relevant studies in two stages, looking first at studies that had been included in previous, readily identifiable reviews of functional or health literacy and health outcomes, then applying a sophisticated supplementary search strategy to relevant electronic databases.

The first search for readily identifiable reviews was conducted using the key terms “health” AND “literacy” AND “review” in MEDLINE, CINAHL, British Nursing Index, EMBASE, ERIC and PsycINFO.

I developed a second search strategy to check for any relevant studies that had not been included in previous reviews, covering the following databases:

MEDLINE 1950 - December 2008; CINAHL 1982 - December 2008; British Nursing Index 1994 - December 2008; EMBASE 1980 - December 2008; ERIC 1965 - December 2008; PsycINFO 1967 - December 2008; and ASSIA 1987 - December 2008.

**Table 1: Inclusion criteria for papers**

<b>Participants</b>	<p>Inclusion – At least 95% of participants age 16-65</p> <p>At least 95% whose first language is the dominant language of the study country/setting</p> <p>Exclusion - Adults who do not speak the dominant language of the study country or for whom this is a second language</p> <p>Adults with reduced literacy skills known to be associated with pathology, such as stroke patients, brain and head trauma patients, people with diagnosed dementia, congenital conditions, people with a learning disability</p> <p>Studies carried out in developing countries</p>
<b>Study designs</b>	<p>Any observational study, including cross-sectional, cohort and case-control, examining relationships between measured literacy and aspects of healthcare or health</p> <p>Any experimental study testing differences in health experiences according to literacy level (Different literacy levels should be demonstrated in categories or on a continuum using a validated tool to measure functional literacy/health literacy/reading ability/numeracy)</p> <p>Qualitative studies which explore the relationship between low literacy and health</p> <p>(Qualitative data should be collected from adults with low literacy as demonstrated by testing or adults participating in basic skills education. It should examine experiences of healthcare and/or health)</p>
<b>Outcomes</b>	<p>Self-management of health problems - adherence; management of long-term conditions; management of acute conditions; knowledge of condition; knowledge of treatment regime</p> <p>Preventive health – health behaviour; attitudes; knowledge Access to and use of formal health services – type, frequency and appropriateness of access; experiences of use Health status - morbidity or mortality; functional status; health-related quality of life</p>

I built up each search strategy using key terms associated with the inclusion criteria, tailored for each electronic database. Although some search terms were common to all search strategies, adjustments were made to take advantage of the different indexing terms available within individual databases, and to add a health focus to those databases that did not have this by default e.g. ERIC.

In order to ensure that as many studies as possible were identified, the search strategy was designed to have high sensitivity even though this would likely be at the cost of reduced specificity. A key contributor to this was the decision to include studies indexed by the term 'educational status' even though most of these studies related to years of schooling. Individual search strategies are included at Appendices 1 to 7.

#### ***2.4.3.3 Exclusion by title***

The first stage of the review was to examine the citations revealed by the various searches and to exclude those which clearly did not meet the inclusion criteria. This applied to titles: which focused on minority or older populations; were studies of children; were set in developing countries; had clearly measured schooling rather than literacy; or otherwise focused on topics or populations listed in the exclusion criteria but had not used key terms which matched the search terms for exclusion.

#### ***2.4.3.4 Abstract appraisal***

For the citations that remained after exclusion on the basis of title, abstract appraisal was carried out. Again, papers were excluded if it was clear from the abstract that they did not fit the inclusion criteria or did fit the exclusion criteria for the review. Those which appeared to fit the criteria or for which this was unclear from the abstract went on to the next stage.

#### ***2.4.3.5 Full text appraisal***

After title exclusion and abstract appraisal, I obtained full text versions of the remaining citations. Most were accessible electronically, the remainder were ordered through the University of Dundee library or on several occasions received after contacting the authors directly. My supervisors carried out independent appraisal of any papers about which there was uncertainty over inclusion and of a sample of the other papers which had been included for full text appraisal. There was a high level of agreement over the inclusion/exclusion of the latter.

#### ***2.4.3.6 Data extraction***

Data relating to study design, populations, sampling, functional or health literacy levels and health outcomes were systematically extracted from each paper which fulfilled the inclusion criteria after full text appraisal. Key findings from the data extraction are presented in Table 2 and the full list of factors extracted is shown in the Data Extraction Form at Appendix 8. Differences were considered to be statistically significant at  $p < .05$ . Otherwise, results are reported as not significant, even if the authors of the particular study considered a different level to be statistically significant.

#### ***2.4.3.7 Quality assessment***

Quality was assessed but not scored due to the small number of papers included in the final stage of review. Quality indicators were recorded for individual papers included after full text appraisal (Appendix 9). If quality issues were recorded for a particular study, these were transferred to the main Data Extraction Form (Appendix 8) and were taken into account in synthesising the findings. Some of these are discussed later in this chapter.

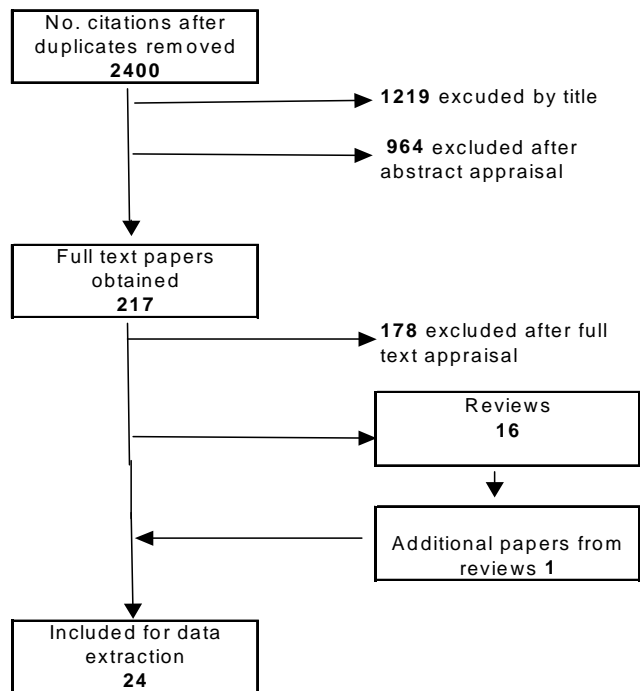
Due to the highly diverse nature of populations and health outcomes investigated; and differing health literacy measures and cut-off points to make comparisons, the findings were not compatible and did not lend themselves to meta-analysis. I therefore undertook a narrative synthesis which follows.

## ***2.5 Results of the systematic review***

A total of 24 relevant papers were included in the review. The initial stage of the search strategy identified four reviews that focused on health outcomes among the age groups of interest.<sup>71, 119-121</sup> Of the 57 primary studies included within these four reviews, 11 met the inclusion criteria for this review.

The second stage of the search strategy identified 2400 citations. Figure 3 shows the number of documents excluded at each stage. Additional reviews identified at this stage were also searched for primary papers not appearing in the citations from the database searches. Exclusions at full text appraisal stage were largely due to studies not meeting the criteria for age or ability to speak the dominant language.

The 11 studies identified from the initial reviews were also identified by the second stage search. The 2400 citations from the second stage search yielded an additional 13 studies that met the inclusion criteria.

**Figure 3: Identification of studies**

The twenty-four papers that were included reported mainly on studies conducted in the USA (21 papers) with two from the UK and one from Canada (Table 2). Studies used diverse methods to investigate the implications of functional or health literacy for various health-related issues in a range of healthcare contexts. I grouped the health related issues that were considered in the twenty-four papers into one or more of five outcome categories reflecting the five areas of interest in the review questions. An additional category of 'emotional responses' that it seemed inappropriate to treat simply as examples of (end state) health status emerged during the process and was included. (Table 2).

Three measures of health literacy (REALM, TOFHLA and s-TOFHLA) and two measures of functional literacy (NART and TABE) were used across the 24 papers included in the review (Table 2). Implementation of the measures and cut-off points to determine low health literacy differed even when the same measure was used (Table 2).



In examining the indicators considered as measures of quality, all but three papers<sup>122-124</sup> considered potentially confounding demographic factors in their analysis. Only two papers<sup>125, 126</sup> clearly reported that the person who assessed health data was blinded to study participants' health literacy status.

I now summarise the key findings relating to each of four health-related outcome domains: health status; health promoting or health risk behaviours; access to and use of health services; and self-management of health problems. These are followed by summaries of key findings in relation to: knowledge of risk or health conditions as a mediator between functional or health literacy and health behaviours; and an additional category of emotional responses which emerged during the review process.

### ***2.5.1 Relationship between functional or health literacy and health status***

There is some evidence from 3 cross-sectional studies that lower functional or health literacy is associated with poorer health status, assessed by self-report or more objectively.<sup>87, 91, 127</sup>

Studies of 1892 emergency department walk-in patients and of 339 people living with HIV-AIDS both found that those with lower health literacy were significantly more likely to self-report their health as poor.<sup>87, 127</sup> In the study of people with HIV-AIDS, recorded CD4 cell counts and undetectable viral loads in the medical notes confirmed the poorer health status of those with lower health literacy.<sup>127</sup> Both studies used the TOFHLA to measure health literacy but compared different cut-off points: Baker et al.<sup>87</sup> compared the highest and lowest of three health literacy levels (0-59 vs. 75-100) while Kalichman et al.<sup>127</sup> compared those above and below 80% correct.

A third study measured reading level using the TABE in 193 adult learners. Those with very low reading levels (at or below 4<sup>th</sup> grade), had significantly lower scores on the physical and psychosocial domains of the Sickness Impact Profile than those with higher (5<sup>th</sup> grade+) reading levels.<sup>91</sup> This study used an objective measure of health but focused on a group of people who were motivated to address their literacy difficulties and so were not necessarily representative of the general population with low literacy. People who have sought help with literacy may be more likely to let health professionals know they have difficulty with reading and writing. Psychosocial health impairment may be more prevalent in those who do not seek help with literacy education and so may be underestimated by this study.

### ***2.5.2 Relationship between functional or health literacy and health promoting or health risk behaviours***

Five studies were found to have investigated the relationships between health literacy levels and preventive health or health risk behaviours.<sup>123, 128-131</sup> All used the REALM to measure health literacy but no two used the same levels for comparison. Findings from these studies were complex and mixed.

Two studies found some higher health risk behaviours in those with lower health literacy but also some potentially conflicting evidence.<sup>123, 128</sup> In a US study of 130 women referred for colposcopy after abnormal pap smear, those with higher health literacy reported a greater number of risk factors for cervical cancer. Differences for individual risk factors varied; those with higher health literacy were more likely to report oral contraceptive use and having had 5 or more sexual partners in total while those with lower health literacy had higher parity. Health literacy was not associated with intercourse aged  $\leq 18$  years or with history of sexually transmitted disease other than HPV.<sup>128</sup> One UK study of 505 family planning clinic users, found that women with lower health literacy were: more likely to have been aged under 16 at first

sexual intercourse; less likely to have used contraception at that time; and more likely to have had two or more partners in the previous 6 months.<sup>123</sup> The UK study of family planning clinic users found no significant difference across health literacy levels in planned or unplanned pregnancies, previous use of emergency hormonal contraception; or number of sexual partners in the previous four weeks.<sup>123</sup>

Comparison of these two studies is difficult because they categorised health literacy levels differently. Although both used the REALM, in the US study, participants fell into a broad range of health literacy levels and those scoring below 9<sup>th</sup> grade were compared with those at 9<sup>th</sup> grade or above.<sup>128</sup> The UK study converted the scores to UK reading ages; all participants had a reading age of 12 and above and comparisons were made between those with a reading age of 12-14 and 15+.<sup>123</sup> This may explain some of the variance in the findings; however, the studies also differed in the age by which first sexual intercourse was reported and the time period over which previous sexual partners were considered. Sexual health behaviours may also have been subject to different cultural influences in the two study settings. Multivariate analysis was not carried out in the UK study but the authors of the US study considered years of education, knowing someone with cervical cancer and having previous colposcopy as potential confounding factors.

Multivariate analysis from two further US studies found no association between health literacy and health risk behaviour. In a study of 600 pregnant women, no correlation was found between reading level and smoking prevalence.<sup>129</sup> In this group, race was significantly associated with smoking practice, African American women being significantly less likely to smoke and being significantly more likely to have lower health literacy. In a study of 423 female prison inmates, many of whom had dropped out of school, HIV risk behaviour was associated with educational attainment but not with health literacy.<sup>130</sup> One of the studies<sup>130</sup> compared 3 and the other<sup>129</sup> 4 health literacy levels across the REALM score.

In a further US study, lower health promoting behaviour in those with low literacy did not reach statistical significance. A cross-sectional study of 61 new mothers found that those with lower health literacy were less likely to initiate and sustain breastfeeding for the first two months of their infant's life. Breast feeding for at least two months was associated, but not significantly, with higher (12<sup>th</sup> grade+) health literacy.<sup>131</sup> This study had an insufficient number of participants and only two literacy categories, 7<sup>th</sup>- 8<sup>th</sup> grade and 12<sup>th</sup> grade+ and this may have contributed to the lack of statistical significance.

This small group of 5 studies did not produce convincing evidence of a clear association between functional or health literacy and preventive health or health risk behaviours.

### ***2.5.3 Relationship between functional or health literacy and access to and use of health services***

One small qualitative study of 8 adults who participated in a community college literacy program and had been hospitalised met the inclusion criteria.<sup>132</sup> Participants had experienced impaired decision-making and given uninformed consent to interventions. They reported having been unsure of what was expected of them as patients because they had been unable to read instructions, for example, on menus and notices.<sup>132</sup> They experienced fear; worry; powerlessness; stigma; vulnerability; diminished self-efficacy in accessing health services, and they balanced the risks of exposure of their literacy difficulties (stigma, decreased self-esteem) with the risks of non-disclosure (lack of knowledge gathering). Some, however, felt that the hospital was a special place where vulnerability could be shared and staff would keep information confidential.<sup>132</sup> I assessed this study to establish what issues were identified in relation to the research questions and to ascertain whether any of

these had been investigated in the quantitative studies. The frequency and distribution of these issues were not explored in the quantitative studies.

A further 6 quantitative studies focused on access to and use of health services. Two studies found no evidence<sup>122, 126</sup> and one found some evidence<sup>87</sup> of associations between health literacy and uptake of services. One study found an association between low health literacy and poorer access to treatment<sup>127</sup> in some cases. Evidence of association between health literacy and relationships with healthcare staff was mixed and unclear.<sup>133, 134</sup>

A study of 543 parents found, as a secondary outcome measure, no correlation between total REALM score and accessing of preventive services for their children.<sup>126</sup> This could also have been considered as health promoting behaviour. A study of 202 African American women's use of prenatal care found no difference between high and low health literacy groups in the proportions of women beginning prenatal care. This study was underpowered, however, and had sought to exclude women who had no prenatal care notes.<sup>122</sup>

Evidence from three studies suggested that low health literacy - as measured by the TOFHLA - may be associated with less appropriate use of health services or access to optimum treatment. A cross-sectional study of 1892 people attending an emergency walk-in department found that those with inadequate health literacy were more likely to have been hospitalised in the previous year than those with adequate health literacy<sup>87</sup> although their more frequent use of health services in general was non-significant after adjustment for age, economic indicators and health status.<sup>87</sup> A study of 339 people with HIV-AIDS found those with lower health literacy were less likely to have been prescribed antiretroviral medication.<sup>127</sup> A further study reported an association between health literacy and relationships with healthcare staff, which may have implications for ensuring access to optimum

treatment. Among 294 people living with HIV/AIDS, those with lower health literacy were no less likely to say that the doctor answered all their questions, but they were significantly less likely to say their doctors asked their opinion about treatment, or that they explained things so they could understand.<sup>134</sup>

Collectively these 6 studies suggest that in relation to health service use, the differences between people with higher and lower levels of literacy are to be found less in terms of initially gaining access to services and more in terms of the appropriateness of patterns of use and the securing of appropriate treatment.

Relationships with healthcare staff featured in an additional study of 157 parents of children aged one to four who had visited a well-child clinic. Those with a REALM score below 9<sup>th</sup> grade self-reported higher quality patient-provider relationships compared to those with scores of 9<sup>th</sup> grade or higher, through better family-centred care, helpfulness and confidence building.<sup>133</sup>

#### ***2.5.4 Relationship between functional or health literacy and self-management of health problems***

Eight studies examined associations between functional or health literacy and aspects of self-management of manifest health problems.

Four studies used quantitative techniques to assess adherence to medication and reported a relationship between lower functional or health literacy and poorer adherence,<sup>135-138</sup> two of them in relation to parents administering medication to their children.<sup>137, 138</sup> A further two studies focused on parental ability to administer medication to their children.<sup>126, 139</sup> One study investigated women's compliance with follow up treatment.<sup>125</sup>

One qualitative study of 25 people infected with HIV investigated the perceived clarity and level of difficulty of self-report HIV medication adherence measurement

tools. Patients found it difficult to define adherence, had difficulty identifying medication and in recalling missed doses.<sup>140</sup> These difficulties have implications both for patients' adherence and for research that seeks to investigate this.

Studies of people living with HIV/AIDS found that in a sample of 381 people, those with lower health literacy were significantly more likely to miss at least one dose of medication over a 2 day period<sup>135</sup> and in another study of 87 HIV+ patients, that higher health literacy was associated with 95% or greater adherence over 3 months.<sup>136</sup> The two studies used different health literacy measures, Kalichman et al considering low health literacy to be less than 86% correct on the TOFHLA<sup>135</sup> and Graham et al comparing those with a REALM score below 9<sup>th</sup> grade level with those 9<sup>th</sup> grade or above.<sup>136</sup> Both studies considered relatively small variations in adherence but findings were consistent over the two widely different timescales.

In a retrospective cohort study of 150 parents of children with asthma, those with low health literacy had used rescue medication for their children more frequently and in greater amounts. They also had a significantly greater incidence of hospitalisation and days missed from school as well as an increase in emergency department visits which approached significance.<sup>137</sup> In a cross-sectional study of 78 children with type 1 diabetes, glycemic control was correlated with mothers' functional literacy as measured by NART scores.<sup>138</sup>

In one cross-sectional study of 181 parents and caregivers, those with lower health literacy, measured by the TOFHLA, reported greater use of nonstandardised dosing instruments to give their children medication and this may impact on their adherence to the medication.<sup>139</sup> Another study of 543 parents found no association between parents' total scores on the REALM and their ability to administer their child's medication.<sup>126</sup>

Compliance with recommended follow-up interventions was the focus of one study of 68 women who had had an abnormal pap smear. This study considered both physicians' subjective assessments of women's health literacy and more objective measurement using the REALM. Although there was a high level of agreement between the two, only subjective physician assessment of patient health literacy was a significant predictor of failure to follow up.<sup>125</sup>

### ***2.5.5 Knowledge of particular health risk or health conditions as a mediator between functional or health literacy and health behaviours***

Twelve studies focused on or included associations between functional or health literacy levels and knowledge about health conditions or treatment<sup>126, 127, 134, 136, 137, 139-141</sup> or health risks.<sup>123, 124, 129, 142</sup> Most, but not all of the studies, demonstrated lower knowledge of the various topics of interest in those with lower health literacy; two studies found that knowledge did not necessarily mediate behaviour<sup>129</sup> or adherence.<sup>136</sup> One study found that lack of knowledge was associated with behaviour likely to impact on adherence but adherence itself was not assessed.<sup>139</sup>

Knowledge of HIV/AIDS in 372 patients offered HIV testing was poorer in those with lower health literacy.<sup>141</sup> One paper reported that in a sample of 294 people living with HIV/AIDS, those with lower health literacy were significantly more likely to believe that HIV transmission was less likely if anti-HIV medication was taken or if viral load was undetectable.<sup>134</sup> Poorer knowledge of their health status,<sup>127, 134</sup> poorer knowledge of medication;<sup>140</sup> and more mistaken beliefs about their treatment<sup>136</sup> were also reported among patients with HIV/AIDS and lower health literacy.

One study of 181 parents and caregivers found that those with lower health literacy lacked knowledge about weight-based dosing and this was associated with the use of nonstandardised medication dosing instruments, mentioned above.<sup>139</sup> Another study of 150 parents reported that low health literacy was associated with less



parental asthma related knowledge, characterised by a two point difference in a 20 point questionnaire.<sup>137</sup>

A study of 600 pregnant women reported that those with lower reading levels had lower knowledge and less concern about the health effects of smoking on their unborn babies.<sup>129</sup> Other studies of 406 women in the community<sup>142</sup> and 505 female family planning clinic patients<sup>123</sup> found women with low health literacy were more likely to want to know more about birth control;<sup>142</sup> had lower knowledge of sexually transmitted infections;<sup>123</sup> and were less likely than those with adequate health literacy to know about fertile times within their menstrual cycle.<sup>123, 142</sup>

The 10 studies which found associations between knowledge of specific health issues and health literacy used 4 different measures and 8 different cut-off points for comparison, so although results suggest that knowledge is related to health literacy, (as would be expected, given the definition of health literacy), as with other relationships with health outcomes, it is unclear what aspects or levels of health literacy are most important.

Two studies found no association between knowledge of health issues and health literacy score. One study found that among 543 parents, knowledge of their child's diagnosis, medication name, purpose and instructions for use was not associated with health literacy score.<sup>126</sup> In this particular study, parents with lower health literacy considered their child more sick for the same degree of illness compared with those with higher health literacy and this may have had an impact on parental management of their child's medication.<sup>126</sup> Another paper reported that among 400 women attending a family planning clinic, knowledge of contraception was generally poor, and although it tended to be better in those with higher health literacy, understanding of side effects of oral contraception and what to do about multiple

missed pills was not associated with health literacy.<sup>124</sup> It is unclear why this particular study differs from the others with a similar focus examined here.

Two studies compared knowledge with related behaviour. One found that knowledge did not mediate smoking behaviour among pregnant women. Those with higher health literacy had greater knowledge but the trend was towards higher smoking in this group although the relationship was not significant.<sup>129</sup> Another study reported that some beliefs about medication did not mediate the relationship between health literacy and adherence and although beliefs about adherence norms were associated with adherence itself, this was independent of health literacy.<sup>136</sup>

### ***2.5.6 Emotional responses***

A further two studies focused on emotional responses of patients, either to their actual condition<sup>128</sup> or to scenarios related to their condition.<sup>143</sup> Although emotional wellbeing can be considered as a contributory indicator of health status, I have reported these studies separately because it seems important not to obscure the possibility that the 'outcomes' they report might mediate other health status changes. Among 130 women identified as being at risk of developing cervical cancer, those with lower health literacy were more likely to have excessive levels of distress.<sup>128</sup> In a sample of 294 people living with HIV/AIDS, those with low health literacy had greater symptoms of affective depression but less evidence of negativistic thinking; they were more likely to endorse feelings of emotional distress, lower optimism and maladaptive coping when presented with a scenario of increased viral load.<sup>143</sup>

**Table 2. Key findings from data extraction of review papers**

Lead author (date), country	Design	Sample size and origin	Language	Functional or health literacy measure (Comparison made)	Outcome category(ies)	Outcome summary
Arnold (2001), US[30]	Cross-sectional; CL Face-to-face interviews	600 pregnant women outpatients at obstetric clinic; Convenience and quota to ensure equal White/African American	English (assumed)	REALM  ( $\leq$ 3rd grade; 4th-6th grade; 7th-8th grade; 9th grade+)	Health promoting/risk behaviours; Knowledge	Reading level not correlated with smoking prevalence in pregnant women. Women $\leq$ 3 <sup>rd</sup> grade level less knowledgeable about potential for adverse health effects for mother and for baby and what these might be ( $p < .001$ ). Low literate women least knowledge about effects of second hand smoke on children ( $p < .001$ ). Women 9 <sup>th</sup> grade+ level more likely to be extremely concerned about health effects of smoking on their babies compared with $\leq$ 3 <sup>rd</sup> grade (66% vs. 37%, $p < .001$ ).
Baker (1997), US[26]	Cross-sectional; DW Face-to-face interviews	1892 emergency department walk in outpatients in two centres (Atlanta (N=979) and Los Angeles (N=913)); Additional 767 Spanish speakers; Convenience	English and Spanish; analysed separately	TOFHLA  (0-59 inadequate; 75-100 adequate)	Health status; Access and use health services	Results for total English speaking patients: Inadequate health literacy patients more likely to self-report health as poor compared with adequate health literacy (Adjusted OR 2.19, 95% CI: 1.34-3.59).  to Atlanta (N=979) Greater likelihood of hospitalisation for of inadequate vs. adequate health literacy (Adjusted OR 1.53, 95%CI: 1.39 to 2.76) No differences in ambulatory care use after adjustment.
Bennett I (2006), US[21]	Cohort; Focus groups clinical	202 postnatal women hospital inpatients; Sequential	English (assumed)	REALM  ( $\leq$ 6th grade; 7th grade +)	Access and use health	No significant difference between women with low and high of health literacy in beginning prenatal care after the first trimester (70% v. 59%; $p = .257$ ); or scoring on the Adequacy

	records	convenience			services	of Prenatal Care Utilisation Index (58% v. 49%; p=.341).
Brez SM (1997), Canada[33]	Multiple case study; structured interviews and participant observation	8 adults in community college semi-literacy program; Self-referral or reputational referral to study	Ability to speak English fluently	Placement in literacy program (No comparison)	Access and use of health services	Participants had found uninformed consent an issue; and of reported feelings of powerlessness and vulnerability. They balanced risks of disclosure of literacy difficulties to healthcare staff against risks of non-disclosure.
Davis TC (2006), US[23]	Cross-sectional; Face-to-face interviews	400 women attending family planning clinic; Convenience	English (assumed)	REALM (<=6th grade; 7th-8th grade; 9th grade+)	Knowledge	Knowledge of contraception and oral contraception generally poor but higher in groups with higher health literacy level. Poor understanding of side effects of oral contraception or multiple missed pills regardless of health literacy level.
DeWalt (2007), US[38]	Retrospective cohort; Face-to-face interviews	150 parents of child with asthma; Convenience	English main language	REALM (<9th grade; 9th grade +)	Self-management of health problems; Knowledge	Children of parents with low health literacy used more frequent (mean days per week 2.7 vs. 1.5, p=.01) and greater weekly dosage (mean 6 vs. 3 doses, p<.03) of rescue medication; less controller medication but difference NS; had greater incidence of hospitalisation (adjusted IRR 4.6; 95% CI 1.8 to 12); days missed from school (adjusted IRR 2.8; 95% CI 2.3 to 3.4) and emergency department visits (adjusted IRR 1.4; 95% CI 0.97 to 2.0). Low literacy associated with less parental asthma-related knowledge (14 vs 16 correct out of 20, p<.001).
Gazmararian JA (1999), US[43]	Cross-sectional; Face-to-face interviews in home	406 community women enrolled in healthcare community Random sample;	97% English (assumed)	s-TOFHLA (<80% correct; 80%+ correct)	Knowledge	Women with lower health literacy more likely to want to know more about birth control (OR 2.2, 95% CI: 1.1-4.4) and more likely to have incorrect knowledge of when they were most likely to become pregnant (OR 4.4, 95% CI: 2.2 – 9.0).

## Phone call to recruit

Graham (2007), US[37]	Cross-sectional; Face-to-face interviews and pharmacy records	87 HIV- infected clinic outpatients; Sequential convenience	English (assumed)	REALM (<9th grade; 9th grade +) (Total score)	Self-management of health problems; Knowledge	Higher health literacy associated with greater likelihood of 95%+ adherence to medication (64% vs. 40% p<.05) over 3 months. Three out of 7 mistaken beliefs associated with health literacy; Adherence norms associated with adherence independent of literacy and did not mediate the relationship between health literacy and adherence.
Hicks G (2006), US[42]	Cross-sectional; multiple choice questionnaire interview	372 patients offered an HIV test by their providers at urgent care centre; Convenience	Ability to read English	REALM to (<=6th grade; 7th grade +)	Knowledge	HIV/AIDS knowledge strongly associated with patients' health literacy (ANOVA p<.001, adjusted R <sup>2</sup> =0.1354).
Kalichman (1999), US[36]	Cross-sectional; Face-to-face interviews	318 HIV positive adults living in community; Provider referral; Word of mouth and self-selection through flyers	Fluent English speakers	Adaptation of TOFHLA reading comprehension scale (<=85% correct; 86%+ correct)	Self-management of health problems	Those with lower health literacy more likely to be non-adherent (at least one dose missed over previous 2 days) to highly active antiretroviral therapy (HAART) (OR 3.9, 95% CI: 1.1-13.4).

Kalichman (2000), US[27]	Cross-sectional; Questionnaire (oral required) S Face-to-face interviews	339 HIV positive adults living in community; if Provider referral; Word of mouth and self-selection through flyers	Fluent English speakers	TOFHLA reading comprehension scale (Cut-off 80% correct)	Health status; Access to and use of health services; Knowledge	HIV-AIDS patients with lower health literacy had lower likelihood of undetectable viral load ( $p<.01$ ); lower CD4 cell counts ( $p<.05$ ) and more likely to have CD4 cell count $<300$ cells/mm <sup>3</sup> ( $p<.04$ ); perceived their health as poorer ( $p<.03$ ); and less likely to be on antiretroviral medication ( $p<.02$ ). Lower literacy associated with poorer knowledge of CD4 count ( $p<.05$ ) or viral load ( $p<.01$ ) and poorer AIDS-related disease and treatment knowledge ( $p<.01$ ). HIV-AIDS patients with lower health literacy less likely to know their CD4 cell count (AOR 1.9, 95% CI 1.1-3.5); less likely to understand meaning of CD4 cell count (AOR 1.7, 0.9-3.3); less likely to know their viral load (AOR 2.3, 95% CI 1.3-3.9); less likely to understand meaning of viral load (AOR 2.2, 95% CI 1.1-4.8) Difference in 3+ hospitalisations for HIV NS after adjustment for time since testing positive. No significant difference in diagnosis with neurological conditions. Those with lower health literacy more likely to believe medical care not good but difference NS.
Kalichman (2000), US[44]	Cross-sectional; S Face-to-face interviews	294 HIV positive adults living in community; Provider referral; Word of mouth and self-selection through flyers	Fluent English speakers	TOFHLA reading comprehension scale ( $\leq 85\%$ correct; 86%+ correct)	Emotional responses	HIV-AIDS patients with lower health literacy had greater symptoms of affective depression ( $F(1, 290)=16.63, p<.01$ ) but endorsed less negativistic thinking ( $F(1, 290)=10.89, p<.01$ ). Lower health literacy endorsed feeling more devastated ( $F(1, 94)=5.84, p<.02$ ), less optimistic ( $F(1, 94)=8.10, p<.01$ ), afraid ( $F(1, 94)=4.79, p<.03$ ) and adopting several avoidant coping strategies ( $p<.05$ ) when presented with scenario of increased viral load. Lower literacy less social support than higher literacy ( $F(1, 290)=6.95, p<.01$ ).
Kalichman (2000), US[35]	Cross-sectional; Questionnaire (oral required) S (oral required)	294 HIV positive adults living in community; if Provider referral; Word of mouth and self-selection	Fluent English speakers	TOFHLA reading comprehension scale (Cut-off 80%)	Access to and use of health services; Knowledge	HIV-AIDS patients with lower health literacy less likely to report undetectable viral load (OR 2.0 95% CI: 1.1-8.1); more likely to visit doctor at least once a month (OR 2.3 95% CI: 1.2-4.4); less likely to say doctor asked their opinion about treatment ( $\chi^2=10.52, df=3, p<.01$ ) or explained things so they could understand ( $\chi^2=7.91, df=3, p<.05$ ). Differences

		through flyers		correct)			in knowledge of CD4 cell counts and viral load NS. Of those who knew health markers, lower literacy less likely to understand meaning of CD4 cell count (AOR 2.5 95% CI:1.2-5.4)or viral load (AOR 3.4 95% CI: 1.3-9.1). Lower literacy more likely to believe anti HIV medication makes patients less likely to transmit HIV to sex partners (AOR 3.0 95% CI: 1.4-6.3) and safe to have unprotected sex if undetectable viral load (AOR 5.8 95% CI: 2.2-15.5); more likely to state easier to relax about unsafe sex (AOR 6.0 95% CI: 2.6-13.6) and report practising more unsafe sex (AOR 3.4 95% CI 1.5-7.5) because of new treatments.
Kaufman (2001), US[32]	Cross-sectional; Face-to-face interviews	61 patients at public health clinic; Convenience	English first language	REALM (<9th grade; 9 <sup>th</sup> grade+)	Health promoting/risk behaviours;		Mothers with lower health literacy less likely than those with higher health literacy to initiate and sustain breastfeeding for first two months (23% vs. 54%) but difference NS. Breastfeeding for two months associated with health literacy but did not reach statistical significance.
Lindau (2006), US[24]	Cohort; Face-to-face interviews and clinical records (patients). Self-administered ST questionnaires (physicians)	68 female attending ob/gyn continuity of care clinic with abnormal pap4% smear diagnosis; Convenience	Spanish speaking	REALM (<9th grade; 9th grade +)	Self-management of health problems		High level of agreement between physicians' subjective assessment and objective measurement of health literacy (K=0.43, p=0.0006). Patients with inadequate health literacy less likely to follow up after abnormal pap smear within one year but difference NS (Adjusted OR 3.8 . 95% CI: 0.8-17.4). Subjective physician assessment of patient health literacy significant predictor of follow up within a year (Adjusted OR 14, 95% CI: 3 - 65) but not of time to follow up.
Moon (1998), US[25]	Cohort; Face-to-face interviews and clinical records; Follow-up	543 parents accompanying children for acute care outpatient visits across five sites; Convenience	English first language	REALM (Total score)	Access to and use of health services; Self-management		In multiple regression analysis, parental health literacy level (REALM score) did not correlate with use of preventive services Parental understanding of child's diagnosis, medication name, instructions, purpose or ability to administer medication not associated with health literacy. REALM score correlated significantly with parental

	telephone interviews					of problems;	health perception of how sick their child was (r=-.086 p<.01).
					REALM		
Paasche-Orlow MK US[31]	Cross-sectional; Face-to-face interviews	423 women in prison; Convenience	English speaking	(≤6th grade; Health 7th-8th grade; 9th grade +)		promoting/risk behaviours;	No association between health literacy level and HIV risk behaviour.
Rosenthal MS (2007), US[34]	Cross-sectional; Face-to-face interviews	157 caregivers of well-child outpatients pediatric residency clinic; Convenience	English speaking	REALM (<9th grade; 9th grade +)	Access and use of health services		Caregivers with lower health literacy more likely to report to family centred care (79% vs. 61%, p=.03) and helpfulness of and confidence building (79% vs. 57%, p=.01). No significant difference by health literacy level in psychosocial issues, safety issues or anticipatory guidance.
				NART	Self-		
Ross LA UK[39]	Cross-sectional; Clinical measurement	78 families attending diabetic clinic; Convenience	English language	(Error score converted to IQ)	management of health problems		In children with type 1 diabetes, HBA <sub>1c</sub> correlated with mothers' reading scores (r=0.28, p=0.01).
							Women with lower health literacy more likely to have been aged under 16 at first sexual intercourse (57.9% vs. 41.6% p<.001); less likely to have used contraception at first sexual intercourse (83.7% vs 89.8% p<.05); and to have had two or more partners in previous 6 months (19% vs. 9.5% p<.002). Difference in planned or unplanned pregnancies, previous use of emergency hormonal contraception and no. of sexual partners in previous four weeks NS. Women with lower health literacy less likely to identify several STIs (χ <sup>2</sup> = 89.3, df=1 p<.001); to know how STIs are transmitted (giving
Rutherford (2006), UK[22]	Cross-sectional; Face-to-face interviews	505 female family planning attendees; Convenience	English first language	REALM scores matched to UK reading age (12-14 yrs; 15 yrs +)	Health promoting/risk behaviours; Knowledge		



						oral sex $\chi^2= 31$ df=2 p<.001; receiving oral sex $\chi^2= 81.8$ df=2 p<.001; anal sex $\chi^2= 92.1$ , df=2 p<.001) or to know most fertile time of menstrual cycle ( $\chi^2=38.3$ , df=1 p<.001).
Sharp (2002), US[29]	Cross-sectional; Face-to-face interviews and LK clinical records	130 outpatients referred for colposcopy after abnormal pap testing; Sequential English speaking	clinic after pap	REALM (<9th grade; 9th grade +)	Health promoting/risk behaviours; Emotional responses	Women with higher health literacy reported higher number of risk factors for cervical cancer (2.3 vs. 1.8, p<.01) but variation in individual risk. Those with higher health literacy more likely to be using oral contraception (34.7% VS. 12.1%, p<.01) and to have had 5 or more sexual partners (51.4% vs. 25.9%, p<.01). Women with lower health literacy higher parity despite similar age (1.9 vs. 1.2, p<.05). Health literacy not associated with intercourse $\leq 18$ years old or sexually transmitted disease other than HPV. Lower health literacy associated with excessive levels of distress among women at high risk for developing cervical cancer (43% vs. 25%, p<.05).
Weiss (1992), US[28]	Cross-sectional; Questionnaire BD (Sickness Impact Profile)	193 adult learners; Stratified sample by reading	English spoken at home as child	Test of adult basic education a ( $\leq 4$ th grade; 5th grade+)	Health status	Low literacy and poor health status independently associated. Low literacy group had higher physical health score (Adjusted mean 6.2 vs. 2.3, p<.002) and lower psychosocial health score (Adjusted mean 15.4 vs. 8 p<.02) both indicating poorer health on Sickness Impact Profile.
Wolf MS (2005), US[41]	Focus groups	25 HIV- infected clinic outpatients; Convenience a previous cohort	English (assumed)	REALM (<9th grade; 9th grade +)	Knowledge	Patients receiving treatment for HIV infection found it difficult to define adherence; required visual cues to identify medication; and had short recall time frame for missed doses ( $\leq 3$ days). Those with low health literacy skills may find it difficult to respond to existing medication adherence questionnaires.

					TOFHLA		In adjusted analysis, lower reading comprehension and numeracy scores in parents and caregivers were associated with lack of knowledge about weight based dosing (AOR 2.0; p=.03) and reported use of nonstandardised dosing instruments; (AOR 2.4; p=.007) inadequate/marginal health literacy associated with lack of knowledge of weight based dosing for children's medication (AOR 2.3; p=.03).
					(0-74	Self-	
					management	75-of	
					problems;	Knowledge	
					(Total scores)		
Yin HS (2007), US[40]	Cross-sectional; Face-to-face interviews	181 emergency attenders; Convenience	paediatric English and room Spanish; analysed separately	inadequate/ marginal; 100 adequate)			

## ***2.6 Discussion of review findings***

The systematic review identified and summarised the reported associations between low functional or health literacy and health in the hidden population with low literacy as defined for the purpose of this study. It also considered research relating to important moderators and mediators in the relationships between literacy and health, particularly health service use and self-care behaviours. However, studies have not always considered the full range of factors that may mediate or moderate the relationship between functional or health literacy and health, and some of the reported associations may obscure confounding factors.

As anticipated, there is evidence here that in the hidden population, low functional or literacy is associated with poorer health status. These associations with poorer health may be mediated through differential use of services and access to good quality treatment. For example, the higher hospitalisation rates among those with lower health literacy<sup>87</sup> may suggest poorer self-management; patients becoming more ill; presenting to health services at a later stage; or waiting until they are in crisis before they contact services. The lower likelihood of access to a particular treatment such as antiretroviral medication<sup>127</sup> may be associated with patient-provider relationships; poorer communication or diminished self-efficacy in gaining treatment among patients with low health literacy. In contrast to this, one study found no difference in uptake of preventive services for children according to the health literacy levels of their parents.<sup>126</sup> This may be because parents with low literacy may receive information about preventive health from additional sources or because they implement strategies to cope with and ensure they do not reveal their issues with literacy. For example, one of the questions in this particular study asked whether parents knew the date of their next well child appointment. People with low literacy skills may be more likely than those with high literacy skills to memorise appointment dates (rather than rely on checking appointment letters or diaries) to ensure they keep them, and so more likely to score well on this question. However, none of these issues have been studied and it is not

clear whether broader aspects of health literacy such as motivation or ability to navigate the health system have been instrumental.

Evidence of poorer adherence<sup>135, 136</sup> and poorer care of children<sup>137-139</sup> suggests that people with lower health literacy may be less likely to adopt effective health promoting or self-care behaviour. This may not be related directly or exclusively to difficulty with reading and following instructions. Subjective physician assessment of patient health literacy was a significant predictor of failure to attend follow up for treatment<sup>125</sup> and although there was a high correlation between their assessment and objective measures of health literacy, physicians did not correctly assess health literacy levels of all the patients. Some physicians' predictions may have been based on the assessment of other aspects, such as the degree of engagement, attitude and body language of patients. Although these findings suggest that healthcare professionals may be able to assess likely literacy problems among their patients when asked, this is not normally the case in routine practice.<sup>115, 116, 144</sup> Qualitative research suggested that people with lower health literacy could struggle with some of the methods used to assess treatment adherence<sup>140</sup> and this may affect the measurement and reporting of adherence studies in general.

In examining differences in relationships with healthcare staff, it is not clear to what extent these findings reflect differential treatment by staff or differential perceptions of treatment by service users. It is possible that people with lower health literacy may respond differently to questions about quality of service or have different expectations from those with higher health literacy skills.<sup>133</sup> The study of people living with HIV-AIDS who reported differential explanations by doctors about their condition raises the issue that those with lower health literacy may also have reduced opportunities to improve their health literacy.<sup>134</sup>

Other studies have identified a range of patient characteristics which may impact on those with low functional or health literacy accessing services and carrying out self-care activities. Poorer knowledge of health status<sup>127, 134</sup> or medication<sup>140</sup> have been reported, but there is no

evidence presented here that knowledge of a condition or medication has a direct relationship with adherence to treatment and two studies found that knowledge did not mediate behaviour<sup>129</sup> or adherence.<sup>136</sup> The studies of people with HIV-AIDS all recruited participants through the use of flyers or through providers, which may have led to a degree of self-selection and the results may not apply across the population living with HIV-AIDS.<sup>127, 134, 135, 143</sup>

Emotional responses and/or diminished self-efficacy may be mediators in the relationship between health literacy and health.<sup>128, 132, 143</sup> These may be linked with low literacy associated stigma reported elsewhere,<sup>114</sup> as it has been suggested that higher awareness of patient need among healthcare staff may improve patient experience.<sup>126</sup>

This review should be interpreted in the context of several considerations. A large number of papers were initially identified. However, considerable proportions were excluded by title or after abstract appraisal. The inclusion of 'educational status,' occasionally but not frequently used to describe literacy, as a search item, increased the sensitivity of the search but also contributed greatly to the number of papers that were subsequently excluded.

Many of the studies included in this review did not state language eligibility criteria for participants and primary language was assumed from country and ethnicity in several papers. In addition, in some of the included studies, participants were required only to be "English speaking," not to have English as a primary language. (Table 2) Ethnicity, used as a proxy for language, is likely to overestimate the proportion with language difficulties, particularly in groups where there are second or third generation adults. This has probably resulted in some relevant papers being excluded and an underestimation of the effect in the population of interest. However, I deemed this more appropriate because, where language was not explicitly stated, I could not assume the population matched the criteria for the review. Similarly, studies which focused on adults over the age of 65 were excluded but many people over this age do not have reduced cognitive skills which impact on literacy, so

once more some relevant papers may have been excluded. Again, this was deemed appropriate because there was no way of distinguishing among such populations.

The studies used different cut-off points to indicate lower or higher functional or health literacy. The effect of this is unknown and it remains unclear what levels of functional or health literacy impact on health and self-care, whether and to what extent there are thresholds and/or gradient effects in different contexts and in relation to different aspects of health and healthcare. As mentioned in Chapter 1, this has been highlighted as an issue across the body of health literacy research.<sup>104</sup>

Most of the papers in the review reported on studies conducted in the US. The findings may not be generaliseable to other countries. For example, in the UK, use of the National Health Service (NHS) does not require patients to engage in complex funding-related paperwork, and the reduced employment prospects associated with low literacy would not have such significance for access. Nevertheless, the NHS in the UK provides most of its health advice and support for management of long term conditions in written form and patients are expected to read and implement medication instructions and drug warning labels on prescription and over-the-counter (available for general purchase) medicines.

Overall, the findings of associations between lower functional or health literacy and (a) poorer adherence to recommended/prescribed healthcare interventions and (b) poorer health are broadly similar for the hidden population of people with lower health literacy as for people who may have language and/or obvious cognitive/communicative impairments in addition to health literacy difficulties.<sup>71, 119-121</sup> In general, the stigma associated with low literacy and the coping mechanisms implemented by those with low literacy are likely to lead to refusal of many individuals from the populations of interest to participate in research. This may underestimate the prevalence or effects in some studies and particularly in the hidden population on which I have focused.

The associations identified in this review have focused on outcomes, which were categorised for analysis and discussion. There are several plausible pathways by which literacy difficulties may lead to health disadvantage, but it is unclear which are most relevant and they have not been explored in the literature reviewed here nor, as already mentioned, in the wider body of empirical research.

Health literacy in its broadest definition includes knowledge and may also include learning ability rather than reading ability and it has been suggested that learning ability may be the mediator between health literacy and hospital admission.<sup>44</sup> I would argue that if functional literacy were not a prerequisite to health literacy and if health literacy could be improved through information and support without the use of written text, health literacy, in its simplest definition: *“the ability to obtain and process health information,”* could be a mediating variable in the relationship between literacy and health. Other potential mediating variables have been suggested such as health beliefs and locus of control.<sup>89</sup>

There is considerable potential for low functional literacy to lead to low health literacy and to impact negatively on health. Already mentioned, factors which contribute to the existence and maintenance of a hidden population with low literacy also potentially contribute to their ability to function within the healthcare environment and to obtain help or support they may require. These factors include healthcare staff that are often unaware of people's difficulties with literacy and the coping mechanisms employed by those with low literacy.

Perhaps the most obvious problem for people with low literacy in the healthcare environment is the amount of health information and advice that is produced in written form. Many authors have provided evidence of leaflets, forms and discharge instructions being written at a level well above the reading abilities of the patients for whom they are intended.<sup>64, 145, 146</sup> Lack of ability to access, read, understand and implement written information has major implications for health including ability to keep appointments, follow

instructions, act on patient information, implement preventive and maintenance action and correctly use medication

The reliance of the health service on written information means that people may not easily gain the health information they require, depending on what alternative means are available. It has been reported that a lower proportion of adults with Below Basic health literacy got health information from any written source than those with higher levels of health literacy. For example, less than one in five adults with Below Basic health literacy compared with 85% with Proficient health literacy got health information from the internet.<sup>59</sup> Again, there may be a cause and consequence relationship here, since lack of ability to access information potentially prevents the improvement of health literacy and there is a likelihood that access to the internet itself is related to other factors which correlate with functional or health literacy, such as poverty and not owning a computer. It has also been pointed out that those with low literacy skills cannot access health messages aimed at the general public such as those that appear in magazine articles, posters in supermarkets or billboards.<sup>147</sup> This could result in reduced opportunities for preventive action to promote and maintain health in general.

Being a patient in the healthcare environment may also exacerbate low literacy. As has been suggested in the Scottish Executive literacy curriculum framework *"If you are worried that you can't do something then you are going to find it more difficult in a public or workplace context than if you are at home in a relaxed situation."*<sup>148</sup> The 'public place' of the hospital or the GP surgery may add to the anxiety of patients and affect their participation in literacy activities. This is likely to prevent patients from gaining or understanding the information they need, potentially resulting in less than optimal treatment.

It has also been proposed that people who have limited reading ability may have difficulty with oral communication<sup>149</sup> due to limited vocabulary and difficulty following complex sentences<sup>44</sup> and they may not have adequate problem-solving skills.<sup>88, 89</sup> This has the



potential to lead to trouble following instructions, complying with treatments and distrust of new information.<sup>42</sup> Low oral communication skills may also affect the ability of patients to engage with healthcare staff and to discuss diagnoses or treatment options, suggesting that patients may not be able to compensate for their lack of reading ability by asking for oral explanations or by having a meaningful discussion about their particular health issue. Engagement with healthcare staff may also be affected by potential stigma.

Shame and the stigma associated with being unable to fully engage in literacy activities may play an important role in the experiences of low literate patients in accessing healthcare services. The reactions of hospital staff can exacerbate these feelings when they become frustrated or angry when a patient fails to complete a form or read instructions.<sup>101</sup> This suggests that even patients who do not reveal their low literacy skills may be stigmatised because of assumptions made by healthcare staff and others about the reasons for their non-compliance or non-attendance, for example, that they lack motivation or interest in their health.<sup>116</sup>

## ***2.7 Conclusion to this chapter***

It is fairly easy to identify some people who are likely to have literacy difficulties and in turn, these people are likely to be offered help with health related activities which may be challenging for them. Those whose difficulties are less obvious and for whom there may a number of reasons why others remain unaware of their low literacy form a hidden population who may be compromised in their access to healthcare and their self-care activities. However, while the systematic review has identified some evidence of association between low functional or health literacy in the hidden population of people with literacy problems, a number of important questions remain unanswered, in particular, how their low literacy and/or their hidden status affects these health outcomes. There are several plausible pathways in the relationship between low functional or health literacy and health outcomes in this group but none have been explored in the literature. Further research is necessary to

be able to understand the difficulties faced by people within this hidden population in accessing healthcare and in self-care activities and to identify the mediators and moderators in the relationships.

The systematic review described in this chapter was published in BMC Public Health in August 2010.<sup>150</sup>

## **Chapter 3: Exploring the health, healthcare and self-care experiences of adults with low literacy: methodology and methods**

### ***3.1 Chapter Overview***

In this chapter I describe the purpose and design of my primary research to explore potential pathways between low literacy and poor health. The methodology of the study is presented in the context of the theoretical background, followed by descriptions of the methods implemented for the study; the study setting; participant recruitment and consent; data gathering; and ethical considerations. I present the research questions the study sought to explore; describe and explain the development of the topic guide; and describe the method of data collection and analysis of the results. Throughout this chapter, my reflections on the process are documented.

*“One cannot expect positive results from an educational or political action program which fails to respect the particular view of the world held by the people.”*

Paulo Freire<sup>41</sup>

### **3.2 Introduction**

The systematic review in the previous chapter presented evidence of associations between low functional or health literacy and health outcomes in the hidden population, but highlighted that a number of important questions remained unanswered. In particular, it concluded that further research was necessary be able to understand the difficulties faced by people within this hidden population in relation to healthcare and self-care.

While the existing body of research has demonstrated well established associations,<sup>71</sup> the pathways between low functional or health literacy and poor health have not been explored to any great extent.<sup>93</sup> Conceptual models have been offered and developed, but authors have postulated what the causal pathways between low literacy and health outcomes might be from evidence produced through existing cross-sectional quantitative research.<sup>93, 151</sup> There is therefore a need to investigate what links between low literacy and poor health may exist, through exploring the experiences that people within the hidden population with low literacy have in relation to health, healthcare and self-care. Identifying issues associated with healthcare provision and self-care activities would help inform appropriate service responses. With these in mind, the aims of the primary research were developed.

### **3.3 Aims**

The aims of the primary research were to understand the difficulties people with low literacy have in self-care and in accessing health services; to identify the coping strategies they employ; and to help identify ways of addressing the issues they raise. Self-care includes taking care of day-to-day health and minor illnesses as well as self-management of health conditions.

### **3.4 Research questions**

The three research questions were:

1. What are the perceived and experienced pathways between low literacy and poor health?
2. What resources and coping mechanisms do adults with low literacy employ to help them navigate the healthcare system and to carry out self-care activities?
3. What kinds of changes in health service provision might improve service accessibility and healthcare and self-care experiences for people with low literacy?

These aims and research questions form what has been described as an “*intellectual puzzle*,” which should be ontologically meaningful and epistemologically explainable.<sup>152</sup> In order to formulate a research design, the researcher must examine their ontological and epistemological positions,<sup>152</sup> which I consider next.

### **3.5 Methodological considerations**

#### **3.5.1 Ontological considerations**

Ontology is concerned with the nature of reality,<sup>152</sup> in this case, the ‘social reality’ to be investigated. In setting out to investigate the pathways between low literacy and poor health, my view was that individuals have experiences that are meaningful social components of the world and that the social reality of adults with low literacy could be constructed through their reported experiences. In theoretical terms, this fits the ontological stance of relativism, which embraces the belief that reality is only knowable through socially constructed meanings; that there is no single shared social reality, only a series of alternative social constructions.<sup>153</sup>

The belief I hold about social reality stems from my own professional experience. Mentioning low literacy among patients to many people involved in healthcare brings the immediate response that there is a need to ensure the use of Plain English in the production

of information leaflets. This reflects a professional perspective, though not necessarily the view of all professionals, of what ‘the problem’ is and focuses the issue on the written word, neglecting to examine other aspects of either literacy or service delivery. This narrow view of social reality is encouraged by the use of health literacy measures that do not match the broader definitions of functional or health literacy and a considerable proportion of the research literature on the subject has repeatedly reconstructed this same scenario.

My own professional experience in working in Public Health with a focus on health inequalities led me to the belief that social reality differs for different individuals and population groups. The primary research was devised with the intention of going beyond the assumptions often made in interpreting the associations between literacy and health. The imperative in the message from Paulo Freire, quoted at the beginning of this chapter, that action needs to respect the people’s view of the world, endorsed my belief in the appropriateness of exploring the social reality in healthcare contexts as perceived by people with low literacy themselves. My study was planned in the belief that the accessibility of health services and the impact of low literacy on this and other aspects of health could not be known without exploring the experiences of those affected.

### **3.5.2 Epistemological considerations**

Epistemology is concerned with what might represent knowledge or evidence of the social reality to be investigated. Epistemology has been described as *“the principles and rules by which you decide whether and how social phenomena can be known and how knowledge can be demonstrated.”*<sup>152</sup> The researcher’s epistemological answers should connect to the answers to ontological questions so that epistemology helps to generate knowledge and explanations about the ontological components of the social world.<sup>152</sup> In this case, the social reality of adults with low literacy could be explored through first-hand accounts of their experiences associated with health and health outcomes. My epistemological beliefs were reflected in the research questions which sought to explore people’s experiences, which I

believed to be meaningful properties of the social reality therein. Interaction with the people concerned was felt to be a legitimate way of gaining access to accounts of their experiences. However, the data to provide answers to the research questions would require to be generated from interaction, or an interviewing process<sup>152</sup> as the experiences of the individuals concerned could only be recounted.

Through participants recounting these experiences I could gain insight into how their limited literacy might impact on health outcomes. It was anticipated that the experiences of individuals would differ in relation to health status and activities involving healthcare and self-care so that data generation would need to be customised accordingly rather than pre-scripted and/or structured. It would also be necessary to interpret the accounts to produce the required knowledge in relation to the research questions, reflecting interpretivism as an epistemological stance.<sup>153</sup> Interpretivism also considers the impact of the researcher on the research and several epistemological questions relative to this aspect arose after choosing a method of gaining participant accounts. These are discussed later. Consideration of my ontological and epistemological stances suggested that interaction with people from the 'hidden population,' as defined for the purpose of the study, was a necessary approach.

### ***3.6 Research approach***

In seeking to achieve the aims of the primary research, interaction through qualitative interviewing offered an appropriate approach, rather than more structured interviewing or the use of a questionnaire. Any type of data gathering which required the participants to engage in reading or writing activities had to be discounted in this case, so that the creation of texts on the part of the participants, for example, through diaries, was not viable. In any case, I felt that face-to-face interaction with the participants was important in generating the relevant data. Qualitative interviewing would seek to answer questions such as 'how?' and 'why?' rather than 'how many?' or 'how much?'<sup>154</sup> as in the more structured, quantitative approaches which have been implemented in most of the existing research focusing on health literacy



and health outcomes. In this way I hoped to add to the existing body of research by complementing the quantitative findings on the same topic, as suggested by Pope and Mays.<sup>155</sup>

The existing research literature provided abundant evidence of a significant level of low functional or health literacy in various populations and associated poorer health outcomes. Although broader aspects of functional or health literacy have been postulated by some as being on the causal pathway to poorer health,<sup>93</sup> data have not been gathered to explore the links from the perspective of those with low literacy. As already mentioned, assumptions, often directly related to reading ability, may be made about what these links are. Qualitative studies aim to understand social situations from the points of view of those involved<sup>154</sup> and provide an opportunity to construct explanations that explore the depth and complexity of people's social world, an approach which Kvale described as one where the researcher seeks *"to unpick how people construct the world around them, what they are doing or what is happening to them in terms that are meaningful and that offer rich insight."*<sup>156</sup>

Qualitative interviewing thus provided an approach that is: naturalistic, that is, based on data generation; flexible and sensitive to the 'natural' social context rather than experimental;<sup>152</sup> and interpretive, that is, concerned with how the social world is interpreted, understood and experienced,<sup>152</sup> all of which was in accordance with my ontological and epistemological stances. Data generation in this way would allow knowledge to be actively constructed from participant accounts. My view of the way in which social reality could be constructed required an understanding of the depth and complexity of their accounts. Qualitative interviewing provided a distinctive approach to generating knowledge specific to each interview, allowing flexibility and sensitivity to the particular dynamics of each interaction.<sup>152</sup> Cues could be taken from the interview responses and follow up of particular topics and issues undertaken. This approach supported the exploration of potentially complex experiences that may not be clearly formulated in the interviewees' minds, and so would not be suited to standardised questioning.<sup>152</sup> Similarly, making analytical comparisons in the data set would not depend on

asking all interviewees the same set of questions. Indeed, to achieve comparable key data may require asking different questions of different interviewees, although a broad topic guide would be used to ensure coverage of the main areas of interest.

Qualitative interviews can take various forms. Those relevant to the current study appeared to be a choice among in-depth individual interviews, which would essentially be conducted face-to-face, or focus group interviews. Both of these were considered in my selection of the primary method of data collection.

Focus group interviews are normally carried out with around 6-10 participants and are characterised by a non-directive style of interviewing; and with the purpose of encouraging a variety of viewpoints on the topic of interest.<sup>156</sup> Focus groups offered the advantage of group dynamics which may stimulate discussion, help gain insights and generate new ideas on the topic in question.<sup>157</sup> However, I perceived several disadvantages to the use of focus groups as a primary method. They do not afford participants confidentiality and some participants can feel inhibited when others are present.<sup>157</sup> These potential issues were discussed with the adult learning tutors who were to be involved in the recruitment of participants, described later, and it was agreed that they were likely to be concerns for some participants, particularly in a situation where I hoped that they would be able to talk freely about health problems and associated issues. Focus groups thus did not appear to be the most appropriate primary method of data generation.

One-to-one in-depth interviews as an approach potentially overcame the main disadvantages of focus groups and offered additional advantages which were persuasive in the decision-making process to select these as the most appropriate method for the study. Face-to-face interviews would be confidential, and would allow for a greater in-depth exploration of individual perspectives on the topic of interest. Individual face-to-face in-depth interviews were thus selected as the primary method of data generation. As described later, focus groups served a different purpose and played a complementary role in the generation

of data. There were several further epistemological considerations and a number of ethical considerations in the choice of in-depth interviewing as a research method.

### ***3.7 Epistemological and ethical considerations associated with interviews***

#### ***3.7.1 Epistemological issues***

The interview has been described as “*a conversation that has a structure and a purpose*”<sup>156</sup> and a “*guided conversation*”<sup>158</sup> Kvale described the closeness of the research interview to everyday conversation as perhaps implying an “*illusory simplicity*” which has encouraged its popularity as a method of choice in social sciences research. He warned against taking this simplistic approach to interviewing, pointing out that the structure and purpose is determined by the one party, the interviewer.<sup>156</sup> The role of the researcher in the interview process has been raised by many others. It has been pointed out that the interviewer is not a neutral gatherer of data about the social world<sup>152</sup> but an inevitable potential source of bias.<sup>157, 159</sup> Kvale described the asymmetry of power between researcher and participant in the interview process, pointing out that the researcher has a scientific competence, and controls the interview process, through setting up the interview situation; determining the topic; asking the questions; deciding which answers to follow up; and terminating the conversation. He went on to emphasise that the interview ‘conversation’ is, rather than a goal in itself, a means for providing the researcher with the empirical material required for the particular research interest. He further drew attention to the potential for the interviewer to manipulate the dialogue in order to obtain information without the interviewee knowing. Kvale did, however, suggest that the power asymmetry may be countered if participants alter the balance by protesting against, or not answering certain questions.<sup>156</sup> Nunkoosing emphasised the latter perspective, portraying the power to be reciprocal, between the interviewer who is the seeker of knowledge and the interviewee who is the privileged knower.<sup>160</sup>

I felt it was important to ensure that these points were borne in mind while conducting the interviews, so that the interview process was not overly influenced by my values and interests. This was particularly important given the characteristics of the study sample. I anticipated that some of the participants may be fairly vulnerable and may not feel able to assert themselves if they felt uncomfortable or unable to respond to a particular line of questioning. They may also feel detached from the anticipated outcomes of the research. They may not have an understanding of the research process or the idea of a written research report which may not be accessible to them due to their low literacy. In order to help maintain a balance I sought to ensure that I was clear about the purpose of the research and that I enabled the participants to describe their experiences and perspectives in a way that made their contribution relevant to them. This was aided by the use of a broad topic guide rather than set questions and participants were able to expand on topics which held particular importance for them.

Such reflections led me to question whether the power, balanced in favour of the interviewer, can be altered substantially and Nunkoosing raised this point in demonstrating that since it is the researcher who ultimately reconstructs the text of the transcript, the interview process can never be equal.<sup>160</sup> This was re-iterated by Kvale, who described the situation as the interviewer having the “*monopoly of interpretation*” in maintaining control of interpreting and reporting “*what the interviewee really meant*”<sup>156</sup>

Ritchie and Lewis highlighted the interactive relationship between the researcher and the researched, citing the different schools of thought on how the relationship might impact on the findings. One school of thought proposes that findings are mediated through the researcher, thus value mediated, and another suggests that the findings can be negotiated and agreed between the researcher and participants.<sup>153</sup> The stance between these two positions, described as ‘empathic neutrality,’ is proposed by some, who, while recognising that research cannot be value free, advocate that researchers should make their assumptions transparent.<sup>153</sup> To achieve this, researchers should constantly take stock of

their actions and their role in the research process, because they cannot be neutral or detached from the knowledge and evidence they are generating.<sup>152</sup> Reflexivity, or critical self-scrutiny, is important in making the research process transparent.<sup>152, 153</sup>

Consideration of these epistemological issues emphasised for me the importance of being aware of what I brought to the interview. I acknowledged the need to ensure that the findings were reported in a way that fulfilled the purpose of portraying the participants' perspectives of their social world, while accepting that these portrayals were necessarily my interpretation. The notion of "*monopoly of interpretation*" highlighted for me, the difference between producing findings by directly reporting what has been said by the participant and interpreting what has been said in the context of the particular research interest or line of reasoning. I also considered that the researcher's interpretation may characterise the earlier point made about the interviewer obtaining information without the interviewee knowing. It was therefore my intention to be clear about what was directly reported or attributed by the participant and what stemmed from my interpretation of the data. Being transparent in this process has been advocated as a way of demonstrating reliability of the data in qualitative research.<sup>161</sup> In addition, I felt that checking and confirmation of the data would help keep participant contributions central to the research process, and help promote shared ownership of the data as well as ensure robustness of the study.

These points highlighted some new, for me, ethical considerations of the interview process in general, relating to the power asymmetry and more importantly, the possible lack of awareness of its implications on the part of participants. This resonates with the argument put forward by Miller and Bell, who make the point that obtaining ethical approval does not mean that ethical issues can be forgotten but rather that ethical considerations should be ongoing within the research process.<sup>162</sup> Again, in considering participants' potentially low understanding of the research process, it was likely that those who consented to an interview did understand that their participation would contribute to a report of all the responses, as this was explained as part of the recruitment process. However, they were

less likely to consider the potential power of the interviewer and conversely, the potential lack of power on their part in interpreting their account and in publishing the findings accordingly, or whether the interaction was evenly balanced.

Overall, qualitative interviewing was more likely to generate a fuller and fairer representation of the interviewees' perspectives and this potentially provided a more ethical approach in giving more control and better representation to participants.<sup>152</sup> Relevant to this particular study, it also offered an interactive process which did not challenge their ability to engage in literacy activities. Nevertheless other ethical features needed to be considered.

### **3.7.2 Ethical considerations**

This study involved the recruitment of participants who had sought help with literacy learning and so may be considered to come into the category of 'people with learning or communication difficulties.' There were therefore several considerations in terms of ethical issues which needed to be considered and dealt with appropriately.

Potential participants would be at varying levels of literacy and may not be able to read the participant information sheet or a consent form. For this reason, it was planned to carry out recruitment through the tutors at the Adult Learning Centre. The participant information sheet could then be read and explained to all potential participants.

This method of recruitment was planned to help ensure that the study was introduced to people by staff who already knew about their low literacy and with whom they had a supportive relationship. It was considered essential that Adult Learning Centre staff would emphasise that participation was voluntary, that interviews would be confidential, and that their decision whether or not to participate would not affect the support they were given. A very simple consent form was to be used and tutors or project workers were to help those who were willing to be interviewed to complete it as required. This was intended to ensure participant understanding of the purpose of the study and implications of involvement

through an independent recruitment process to overcome any difficulties that would be caused by expecting potential participants to read and understand written texts.

Interviews were planned to be carried out in a conversational style, conscious of the need to avoid undermining self-esteem in relation to literacy difficulties. I recognised that some participants may experience mild psychological distress or discomfort while discussing some of the issues that had caused them difficulty. It was essential that this would be handled sensitively and participants would be given the opportunity to pause, continue at their own pace or not to take a particular issue further. It was also planned that there would be an opportunity at the end of the interview for the participant to ask any questions or to bring up anything they had been thinking or worrying about during the conversation. This was to be done with the digital recorder switched off. I also intended to ensure that the participant was aware that they could get support from the Adult Learning Centre regarding particular literacy issues.

A successful application was made to the Chief Scientist Office of Scotland (CSO) for a small grant to cover aspects of the study including transcription of interviews and office supplies. It was also approved by the CSO that this funding would provide for a £10 store voucher to be given to each participant as a thank you for sharing their experiences. I felt this was appropriate as a small appreciation of the contribution participants, who were likely to be unemployed or on low incomes, were making in sharing their personal experiences of issues that were not always positive and indeed, may have had a negative impact on their lives. There is ongoing debate about the ethics of payment for research participants, for example, suggestions that payment may produce “*undue inducement*”<sup>163</sup> and, with particular reference to qualitative research, the recommendation that the impact of making payments should be considered in research accounts.<sup>164</sup> In this study, the gift voucher was not used as an incentive to participate but was given at the end of the interview. It may be that, over time, new participants were aware of the vouchers being awarded. However, I believed that the value of the voucher was unlikely to encourage unwilling participants to engage and

there was no evidence that those who were interviewed were solely interested in gaining the reward.

Application was made to the University Of Dundee Research Ethics Committee and ethical approval was granted prior to recruitment and data collection (Appendix 10).

### **3.8 Rigour**

Several allegations have been made to the effect that some or all qualitative research lacks rigour. In response, it has been argued that all research, including quantitative research is selective and dependent on, among other things, the researcher and the choice of methods.<sup>165</sup> Systematic and self conscious research design, data collection, interpretation and communication have all been advocated to ensure rigour. In addition, it has been proposed that through creating a clear account of method and data and producing a plausible and coherent explanation of the phenomenon in question, the integrity of the research can be protected.<sup>165</sup> My goal was therefore to adopt a clear, transparent and reflexive research process, as documented in this chapter.

#### **3.8.1 Credibility of the data**

Assessments of reliability and validity cannot be implemented in qualitative research in the same way as they are in physical or mathematical sciences. It has been suggested that reliability is “*rather useless*” for assessing qualitative data<sup>161</sup> and that, as an alternative, reliability meaning ‘sustainable’ and validity meaning ‘well grounded’ can help define the strength of qualitative data.<sup>153</sup>

Reliability in a traditional sense is concerned with replication and the concept is considered by many to be naive and unattainable because of the likely complexity of the phenomena under study; the impact of context; and because of the dynamic nature of qualitative enquiry.<sup>153</sup> This ‘real world’ research makes it difficult to replicate the original conditions or



to control all the variables that might possibly affect the findings.<sup>166</sup> For those and other reasons, such as beliefs about how reality can be captured in the first place, the term 'reliability' is often avoided in qualitative research.<sup>153</sup> Guba and Lincoln offered the term 'dependability' rather than reliability.<sup>167</sup>

Clearly the choice of in-depth interviewing in this study, with the use of a broad topic guide to support conversational style semi-structured interviews did not involve replicating exactly the same instrument to generate data from each person in the sample. However, the data generation followed recognised approaches, paying careful attention to epistemological and ethical issues. It is probable that interview transcripts would be different if different interviewers had carried out the interaction. However, in considering the topics covered, it is likely that the same issues would arise. This is partly supported by the commonality of issues raised across participant interviews, and this may be considered to indicate their dependability.

Validity is concerned with whether the researcher is investigating what they claim to be investigating (internal validity)<sup>153</sup> or explaining what they claim to be explaining (external validity).<sup>152</sup> It is also concerned with the extent to which the constructs or postulates are applicable to other groups, contexts or settings (external validity).<sup>153</sup>

My philosophical stance rejected the realist assumption of the existence of a single external reality for the issues of interest and so it would be inappropriate to judge my findings according to such a single external reality which is often understood as the concern of validity. Guba and Lincoln suggested using the terms 'credibility' (internal validity) and 'transferability (external validity).'<sup>167</sup> and these offer a more appropriate perspective given the philosophical stance and data generation methods.

Focus groups were conducted to provide reassurance of the scope of findings generated from the individual interviews and to check my interpretation, as well as to discuss further the proposed solutions suggested by those participating in the initial interview process. This

helped establish the credibility of the findings and my analysis and interpretation of them. Transferability of insights from qualitative studies is also of particular concern in the context of generalisation of the findings.

### ***3.8.2 Generalisation of the findings***

The nature of qualitative research means that samples are not statistically representative and therefore not designed to extrapolate findings to the general population, so that generalisation can only ever be theoretical.<sup>152</sup> The 'special problem' that qualitative research has in relation to generalisability of the findings is that the starting point is often an analysis in, for example, a particular context, and the reference to the context is given up for analysing how far the results may transfer beyond that specific context.<sup>161</sup>

It has been suggested that, in qualitative research, understanding replaces generaliseability<sup>168</sup> and that clarification of the question of what degree of generalisation is intended within a single study can help derive generalisation.<sup>161</sup> Another suggestion is that the generaliseability of the findings of a study is often closely linked to realising the sample, in that theoretical sampling offers a strategy for designing the variation of conditions under which a phenomenon is studied as broadly as possible. Research questions imply generalisations, and design and practice should support these to strengthen the 'weak argument' that results are generaliseable if there is no reason to assume that those in the sample are atypical.<sup>152</sup>

The sample I recruited was purposively selected to achieve diversity within an accessible group of a previously hidden population with low literacy. This provided a wide age range, both genders, and adults with a variety of healthcare experiences. Again the similarities and differences in the data generated and the breadth of issues raised provided varying perspectives which add to the knowledge of social reality for this population.

### **3.9 Reflexivity**

Reflexivity, or critical self-scrutiny, is important in the research process to ensure that assumptions are made transparent and that the impact the research process has on the participants and the evidence produced is also examined and considered.<sup>152, 153</sup> At this point, it is perhaps appropriate to examine my role in the research, my reasons for carrying out this study and what I brought to the process.

I have worked in Public Health for 18 years, and for the last 9 years my focus has been on demographic information segmented according to deprivation, population profiling, analysis of differential outcomes and the provision of research evidence to support strategic and action planning in relation to addressing health inequalities. This has brought an awareness that literacy has not been considered in the social determinants of health normally included in any examination of associations between social circumstances and health inequality, albeit literacy is associated with variables which are normally included, such as education and employment. I felt strongly that this was a major gap in the research and one which, if explored may reveal an explanatory variable in the different health outcomes that people experience. I have also had a lifelong interest in education and I am an avid reader. However, literacy is mainly concerned with neither education nor reading per se. I was interested in the view that people have of literacy, as well the assumption that would appear to be made by many friends and colleagues that very few people in our society have difficulties with reading. To illustrate this point, when friends, knowing my interest in literacy, say *"I can't imagine not being able to read,"* while I am sure they understand the role that reading plays in day to day life, they often mean that they can't imagine not being able to enjoy a good book. Reading for pleasure is an important activity for many people, but there are many others who have the necessary skills but choose not to read as a leisure pursuit.

The primary disadvantage for people with low literacy is not that they cannot pick up the latest blockbuster novel at the airport but that they may struggle to book their flights, to find

their way around the airport and to follow other written instructions required for them to follow their travel plans. In other words, for people with low literacy, their experience of these social practices can be the same on this side of the trip as it is for others when they arrive at their foreign destination and struggle with written instructions and other literacy-related social practices there.

I therefore began the study with the view that the topic of interest was broad and far reaching in terms of its potential impact on people's day to day functioning rather than to do with skills. I made the assumption that people would be feeling disadvantaged, not because of their low literacy skills but because of the effect that these had on their day to day lives. I also assumed that this would be viewed as a problem by them and I revisit this point in Chapter 6 in discussing issues such as epistemological privilege<sup>152</sup> which relates to whether people have a particular epistemological standpoint in the interaction, for example, disabled researchers researching disability.<sup>56</sup> My awareness of the implications of my view meant that I was also aware that I needed to avoid focusing on literacy as a problem during the interviews and ask broad questions like *"How do you get on with taking your medicine?"* rather than asking people if they were able to read the instructions for their medicine.

My work in Public Health has also involved the evaluation of pilot initiatives, mainly based in disadvantaged communities, designed to improve access to services or otherwise tackle the health inequalities experienced by those communities. Having spent a considerable amount of time talking to people in these communities was an advantage in meeting and communicating with learners, who later became participants and I found it easy and very natural to engage with them. This engagement was important since I felt that it was appropriate to carry out only one interview per participant for reasons of time and effort on the part of the participant. It has been suggested that participants move from 'public' to 'private' accounts over time, so that repeat interviews gain more in-depth and intimate accounts.<sup>169</sup> However, I felt that my experience in putting people at their ease and being able to talk to them in a non-patronising, friendly way helped to generate relevant and appropriate

data. Listening, accepting their views and allowing people to focus on issues they considered to be important or significant were all employed to share control of the interview and help put the interviewee in a position of feeling that their contribution was of value. I believe that without the experience I have had with a variety of communities, I may not have been able to engage with participants in the same way.

### ***3.10 Methods***

#### ***3.10.1 Sampling frame***

Two organisations provided a sampling frame for the recruitment of participants. The first was Dundee City Council Adult Learning Centre, which would enable recruitment of adults who had sought help with literacy. The second was Dundee Healthy Living Initiative (DHLI), a community project working with adults in communities of deprivation. Through working with the latter project in my NHS post, staff who were aware of my interest in literacy research indicated an awareness that many of the people with whom they worked had literacy problems, identified through the use of recognised coping strategies such as making excuses to avoid reading any written material.

#### ***3.10.2 Adult Learning Centre***

Dundee City Council Adult Learning Centre is based in a former primary school building fairly close to Dundee city centre and on a main bus route. Support with reading, writing, spelling, numeracy, basic computer skills and English for speakers of other languages (ESOL) is offered by a team of tutors. Literacy learning through the Centre follows the social practice view<sup>34</sup> and thus focuses on the particular learning needs of individuals. For some, this may, however, involve a starting point of basic reading skills. Others may focus on a particular requirement such as course work for employment or on other literacy-related social practices such as preparing to take a driving theory test. Adults aged 16 and over can access learning through self-referral and referrals are also made by other agencies such as

those offering support with employment or providing various types of community activities. Recruitment or encouragement to access the Centre is also carried out by tutors through outreach work at community events and through community projects. Attendance at the Centre is flexible to accommodate learners' personal circumstances. Learners are tutored in small groups or sometimes individually and mainly attend one or more times a week. Frequency of attendance can vary, however, to fit in with other commitments such as shift work or irregular working hours.

### ***3.10.3 Dundee Healthy Living Initiative***

Dundee Healthy Living Initiative is a community project which aims to promote positive health and wellbeing by delivering health improvement activities as identified by local people in the most disadvantaged communities, using a community development approach. The project, which is funded by Dundee City Council, NHS Tayside and a range of other sources linked to short term health and wellbeing initiatives, provides opportunities and support for local people to meet their own health needs; share knowledge and skills within their own communities; and influence decisions about health service development and delivery. A wide range of activities and groups are provided within local communities by a multidisciplinary team which includes community workers, nurses and trained volunteers, the latter from the communities themselves.

### ***3.10.4 Rationale for the choice of sampling frame***

Recruiting participants via the Adult Learning Centre would clearly exclude members of the still hidden population of adults who had not recognised or sought help for their low literacy. However, I judged this sampling frame to be appropriate for several reasons. It would be very difficult to identify members of the still hidden population in an ethically acceptable manner for research purposes only. It was hoped that recruitment would include some people who had only recently recognised or had someone else identify their low literacy by recruiting via Dundee Healthy Living Initiative, but it was envisaged that most of the

participants would be recruited via adult learning classes. It was anticipated that although these participants *had* sought help with literacy, they were likely to have previously experienced - and may still have – similar problems to those experienced by members of the still hidden population. The fact that they had (at least to some extent) recognised their need for literacy support, and were likely to be making progress with their learning, was potentially advantageous for this study, because they would be able to look back on their past experience with hindsight, and perhaps talk about issues relating to their low literacy that they did not recognise until they acquired a new perspective on them. It was intended that the interview questions would accommodate this.

### ***3.10.5 Participant recruitment and consent***

I met with the manager of the Adult Learning Centre to explain the purpose behind the study and the processes and arrangements required. This achieved agreement that the tutors would carry out the recruitment process and I later contacted individual tutors to explain the study and how they should use the recruitment material. I felt it was appropriate to carry out the interviews as far as possible within the Centre, as people may feel more comfortable there and it was likely to be seen as their ‘territory.’

Similarly, I met with Dundee Healthy Living Initiative project workers at one of their regular team meetings to brief them on the study and arrangements. It was established that in the case of participants recruited through this project, the principle of interviewing them on their own ‘territory’ could be applied through the use of neighbourhood centres and other community venues close to or familiar to individual participants.

It was thus agreed that Adult Learning tutors and Dundee Healthy Living Initiative project workers who had been briefed about the study would carry out recruitment of participants. In the case of Dundee Healthy Living Initiative, workers would, if they felt it appropriate, explain the study and recruit anyone who either revealed their low literacy, or for whom the issue came to light through discussion.

I produced a participant information sheet (Appendix 11) and a consent form (Appendix 12) having sought advice on their content through the Adult Learning Centre. I also sent the draft documents to the Adult Learning Centre for comments and approval for use with potential participants. It was agreed that tutors and project workers recruiting the participants would read and explain the participant information sheet as an invitation to take part in the study, provide background information to the study and answer questions verbally as required. Recruiting tutors and project workers would also help those who were willing to be interviewed to complete a consent form, if required.

I also planned to reiterate the information about the study and check that individuals were still willing to participate at the start of interviews. This method of recruitment is consistent with the principles of adult learning that follow the social practice view of literacy,<sup>34</sup> in acknowledging reading and writing as situated social practices. Many of the adults who attend the Adult Learning Centre or participate in the Dundee Healthy Living Initiative project are used to bringing along written materials and forms in relation to particular literacy-related social activities to be explained and to get support with their completion. In this way, the recruitment process provided support with the broader social practice of participating in research.

Part of the recruitment process, but not the recruitment itself, was changed slightly after the discussion to brief the tutors at the Adult Learning Centre. It was suggested by the tutors that I should come along and meet potential participants at their adult learning classes and describe the purpose of the research and the interview process myself. This appeared to be a good way of helping to allay any fears potential participants may have about talking to someone unknown to them, whom they may view as an anonymous health service manager or someone from the University. Meeting with them would provide an opportunity for me to explain my interest and my reasons for the research.



I therefore arranged to be at the Adult Learning Centre at various times to fit in with coffee breaks in the middle of their learning sessions, when learners came out of the classrooms to gather in a communal area which includes a cafe. I met with various groups and individuals within this area, and chatted with them informally about the research I was hoping to carry out. I gave them the participant information sheets and consent forms, telling them that the tutors would be going through these with them before they should decide whether they wanted to take part in the study.

These initial meetings to establish rapport again raised some additional ethical considerations on which to reflect. Duncome and Jessop called this *“doing rapport”* which they considered to be a way of managing consent by *“faking friendship”* for the express purpose of persuading potential interviewees to participate.<sup>170</sup> Further, they declared that *“‘Doing rapport’ becomes the ethically dubious substitute for more open negotiation of the interviewees’ fully involved consent to participate in the interviewing process.”*<sup>170</sup>

In their discussion of the concept, they offered examples where ‘doing rapport’ had been viewed by researchers as a necessary strategy to achieve consent. They questioned the ethics of such an approach and illustrated associated ethical dilemmas such as participants treating researchers as friends and going on to disclose information which the researcher may find difficult to deal with. I would argue that *“doing rapport”* can be implemented to varying degrees and that in its extreme form, may indeed be tantamount to coercion. There is, however, a difference between *“fake friendship”* and genuine *friendliness* and I would argue that the approach may be influenced by the nature of the motivation associated with carrying out the research. It would seem to be more fitting to question the ethics of any research that was thought to require such persuasive methods to engage with participants.

Others, conversely, have emphasised the importance of developing a good rapport, Ritchie and Lewis describing the relationship created in this process as a ‘working relationship’.<sup>153</sup> and this is how I viewed the connection I sought to develop with participants. My reason for

taking up the suggestion of meeting with learners was undeniably to encourage consent to participate. It has been suggested that individuals who identify themselves as socially excluded or belonging to a marginalised group are unlikely to formally consent in writing to participation in a study.<sup>162</sup> This could be applied to the population of interest in my study and I viewed their potential lack of participation as a missed opportunity for researcher and participant. My belief in the research study as a process to find out what the issues are for people with low literacy in order to inform changes to the health service led me to view the encouragement to participate as a potential advantage to the participants as well as to me as the researcher.

Rapport was also established with the tutors in the Adult Learning Centre and this probably helped greatly in promoting the research as a credible piece of work and myself as an accepted professional. Adult learners, as highlighted in the study do not readily disclose or discuss their literacy issues but expressed positive feelings, support and acceptance at the Centre. It is probable that my rapport with their tutors, which again I viewed as a good 'working relationship'<sup>153</sup> placed me in a position of trust in that environment.

No recruitment took place at the time of my initial meetings with learners so that people did not feel under any obligation. Learners did not have to make a decision about participation without support from someone familiar to them. Indeed, throughout the study I did not personally recruit any participants. The tutors, after implementing the agreed recruitment process, then assigned appointment times to participants, or noted their telephone numbers so that I could call people up and arrange an interview time with them. It could be argued that the tutors thus became the gatekeepers for the study, a situation with its own inherent sources of potential bias.<sup>170</sup> However, this was an option that protected a potentially vulnerable population from feeling obliged to participate while also supporting those who were willing to share their experiences. The initial meetings with learners suggested that, in this environment, they were both keen and able to express their opinions and after

explaining the study directly to them, they were being supported to make an informed choice whether to participate.

### **3.10.6 Criteria for inclusion**

Recruitment through the Adult Learning Centre served the purpose of accessing people with literacy difficulties which had led them to seek help. This meant that the focus was on people with low literacy rather than on people who had particular health experiences. However, I envisaged that there may be difficulties in selecting, through the Centre, people who had long term conditions or frequent contact with health services because they may not want to declare this to their tutors. Focusing on long term health conditions may also have meant that their participation in the study would identify them to their peers as having health problems. Similarly, I felt that those accessing Dundee Healthy Living Initiative activities or groups may not wish to disclose their medical histories to the project workers or their peer project users.

Recruitment through a healthcare setting may have facilitated a greater focus on particular health problems but would have been more problematic because of the low number of potential participants who had revealed their low literacy. I did not consider it necessary to include only people who had health conditions requiring health service access and/or self-care activity since virtually everyone has some experience of healthcare.

Some people have regular acute health service contact and daily self-care requirements for long term conditions, many more people contact their general practice for health advice and treatment and most people will, at some point, have experienced a self-care activity through seeking to purchase or otherwise obtain and use prescribed or over-the-counter medicines. All of these types of healthcare contact, along with self-care and preventive health activities are likely to involve varying degrees of literacy skills, so exploring this range of health activity allowed a broader focus on health and literacy rather than one confined to illness and health service treatment.

Within the chosen sampling frame, there were several criteria for inclusion in the study. Recruitment was restricted to people who used English as a first language. Those whose primary language was not English were excluded because any language difficulties they had would usually be addressed through interpretation and translation (and they may be highly literate in their own language). People who attended the Special Educational Needs classes at the Adult Learning Centre were excluded because they were less likely to be part of the hidden population of adults with literacy difficulties and their needs in terms of addressing these difficulties may be different from the hidden population who are of normal IQ with no obvious communication difficulties but who have low literacy skills.

In order to identify the range of beliefs, experiences and practices within this population a purposive sampling strategy<sup>153</sup> was employed. There is a lack of empirical evidence to firmly indicate the distribution of literacy and health issues. However, I believed that it would be appropriate to sample purposively to ensure the inclusion of participants of both genders, different ages and stages of literacy education as these are known to impact on healthcare behaviours and experiences. I also sought to ensure that people with multiple and enduring health problems across those variables were included. Sampling continued until no new issues were emerging in relation to the research questions.

### ***3.10.7 Participant response***

Twenty five participants were recruited for individual interviews, twenty four through the Adult Learning Centre and one through Dundee Healthy Living Initiative. The lack of engagement with the study through the community project was thought to be because of the difficulties associated with identifying potential participants in a community population of adults who had not disclosed their literacy problems. This was not surprising and confirmed the rationale for sampling from a population who were not completely hidden because they had sought help with their literacy. The one participant who was recruited through Dundee Healthy Living Initiative was completing a course funded through the project and had

disclosed her literacy problems to project staff when she was struggling with the written work. Although she consented and was interviewed through Dundee Healthy Living Initiative, her disclosure of her literacy difficulties had resulted in her referral to the Adult Learning Centre, so that, at the time of interview, she had begun to attend classes there. All focus group participants were recruited through the Adult Learning Centre.

One male learner had agreed to participate but changed his mind before the interview. This information was relayed through his group tutor.

### ***3.11 Data generation – interviews***

I conducted the interviews adopting a conversational style and using a broad topic guide as described below and attached at Appendix 13. It included people's descriptions of their literacy learning, health issues, strategies for and experiences of self-care and accessing and using formal health services, and their ideas about what might make it easier for people with literacy difficulties to get good healthcare.

Interviews typically lasted for around one hour and took place in one of a number of small meeting rooms within the Adult Learning Centre. Rooms were booked for the duration of the interview to maintain privacy and to avoid interruption. Participants either took time out of class or came into the Centre outwith their class hours specifically for the interview. The one interview arranged through Dundee Healthy Living Initiative took place at a church hall, the venue used for a separate community project working with vulnerable young mothers. The space provided for this interview was in a seating area on a landing, which afforded privacy but was less quiet than the individual rooms provided at the Adult Learning Centre. The interviews were audio-recorded using a digital recorder. Although this had been stated on the participant information sheet, I checked with each participant at the beginning of the interview that they agreed to be recorded and there were no refusals.

During the interviews, in light of considering possible ethical issues in working with a potentially vulnerable population, I was alert to participants' emotional responses to what was being discussed. One participant became emotionally distressed during her interview when she was discussing work experiences in relation to her low literacy. I allowed her to pause and take time to gather herself together, assuring her that it was understandable that she felt that way. I then ensured that she was willing to continue with the interview before proceeding further.

Another participant revealed some child protection issues in her own life when she had been younger. She appeared to have coped with these issues and I checked that she had had support at the time. She was not distressed when talking about the situation and at the end of the interview she assured me she had no concerns about what had been discussed. When she returned to her class, I walked through with her and spoke to the tutor regarding another interview. At this point, the participant seemed a little quiet and withdrawn. On returning to my office I called the tutor to check that the participant had been all right after the interview so that she could provide support if necessary. The tutor informed me that the participant was often like that in class and that she had spoken positively about having participated in the research.

At the end of each interview, as intended, I ensured that the participant had no concerns or worries about what had been discussed and asked if they had anything they wanted to say with the digital recorder switched off. At this point, only one participant referred to his particular health problems which he had not wanted to discuss when it was being recorded. This did not alter the content of his interview but gave me an understanding of the type of healthcare he was accessing at the hospital. Also at the end of the interview, participants were given a £10 store voucher, which was funded through the CSO small grant.

When 25 interviews had been completed, no new issues were emerging in relation to the research questions.

### ***3.11.1 Interview topic guide***

I produced a topic guide to use for the interviews, to help ensure coverage of the main areas within the research questions. As such, it was used as a reminder to explore these key topics specifically. The original areas included in the topic guide, as described above, were therefore ones that were pertinent to the research questions and focused very much on health, health service contact and self-care activities (Appendix 13).

The topic guide underwent some development over the period of the study to ensure inclusion of emerging issues in the ongoing interview process. As the interviews were conducted in a conversational style, people included some of their life history in their accounts, particularly raising experiences in relation to their literacy difficulties and how these had affected their schooling or work experiences. Initially I felt that this was part of the interview conversation that I 'allowed' rather than encouraged. It appeared to be important to the participants to relate these experiences and it encouraged them to get the conversation flowing, making it easier to ask subsequent questions about health related experiences. It also fulfilled my response to the epistemological question raised about potential influence of the researcher's values and interests, which was to allow the participants to contribute what was relevant to them in their accounts. As I carried out an initial analysis it became abundantly clear that what people were reporting were experiences which had considerable implications for their mental health. Furthermore, they had either repeated or sought to avoid repeating their early negative experiences in relation to their literacy difficulties and this was often linked, explicitly or by implication, to how they now participated in social situations, including healthcare encounters.

In discussion with my supervisors, the individual interview topic guide was further developed to cover these emerging issues. The additions to the topic guide are included at Appendix

14. The development of the topic guide in this way neither intended nor served to create additional research questions, but rather, generated different answers. This study sought to identify pathways between low literacy and poor health. In doing so, participant accounts pointed to links with mental health, which became a priority area for exploration.

Disclosure management was also a major consideration as both an issue that participants reportedly had to cope with during healthcare consultations and one that appeared to have an impact on several aspects of participants' experiences in a health context. Disclosure management was therefore added to the topic guide including questions such as "How would you decide who you would tell?"; "Who knows about your literacy?;" and "What did you say when you told them?" Advantages and disadvantages to disclosing were added as a possible area of interest in talking about disclosure management (Appendix 14).

Although, in general, early experiences were included naturally in participant accounts, I added life history in a further development of the topic guide paying particular attention to childhood, school and work experiences to ensure that this was captured (Appendix 14).

Later interviews provided opportunities to focus more closely on some of the emerging topics that required more in-depth exploration. Some interviews, for this reason, tended to focus on a smaller range of topics. The expansion of the topics and focus on the issues raised by participants themselves helped produce a data set that was relevant to the population of interest. Steps were then taken to confirm the data generated by this process.

### ***3.11.2 Confirming the data***

Membership checking is a way of confirming the findings by taking them back to the participants to check if they are recognised and verified<sup>153</sup> or to allow for additional comments to be made.<sup>156</sup> This was not practical in the present study for a number of reasons, including the extra time it would take when learners had already taken time out of their classes to participate. Perhaps more importantly, I wanted to avoid difficulties caused



by expecting people who are not confident of their literacy skills to take part in what could be viewed as a literacy activity. It was important, nevertheless, to check that the emerging concepts and themes did represent the meanings and issues conveyed by participants. Discussion of the suggested service solutions was also desirable as they too had emerged over the period of the interviews and warranted further exploration to formulate some meaningful conclusions to the study in terms of informing service policy and practice. At this point, focus groups were the preferred method for a number of reasons.

The decision to include focus group interviews was motivated by the notion of finding a simpler way of confirming the data than the use of individual member checking. The advantage of this method, for the purpose of this particular part of the study, lay in the opportunity to include several participants at one time and in the group dynamics which would hopefully promote discussion and lead to new ideas. The disadvantages which had been identified in employing focus groups in the initial part of the study appeared to be no longer applicable since this was to be a discussion of general themes within the findings rather than one which sought to have in-depth insights to people's own experiences. Also it provided an opportunity to participate for learners who may have felt less comfortable in a one-to-one situation, or may have felt that they did not have a great deal to contribute but could enter into the discussion. In addition, by the time the focus groups were convened, learners in the Centre were aware of the research going on and of the individual interviews being conducted and may have been less wary of participation at that point.

### ***3.12 Data generation - focus groups***

The focus groups were arranged by the tutors at the Adult Learning Centre, implementing the same process as for the individual interviews in explaining the purpose of the study, and going through participant information sheets and consent forms. Five focus group participants had participated in individual interviews and 4 were new to the study. Both focus groups, which took place during class times, were held in one of the classrooms, which

afforded both privacy and a familiar place for participants. The first focus group consisted of 4 individuals who were in the same learning group and so knew each other, although one participant had joined the group only recently. The second focus group was made up of 5 people who were in 3 different learning groups. Learning groups tend to be small, with members receiving a considerable amount of one-to-one support during their learning time. Groups are also flexible and it is not unusual for people to go to more than one group or to change the times of their class to fit in with their personal circumstances so they are not necessarily familiar with only the people in their particular group. Equally, they are not necessarily used to activities conducted as a whole group. The two different arrangements of participants did not appear to have any particular advantages or disadvantages and all of the participants made a contribution to the group discussions.

At the start of each focus group I made it clear that, for those who had participated in one-to-one interviews, what they had already told me remained anonymous and confidential; that I would not refer to it and they should not raise anything that had been discussed in the interview unless they wished to do so as part of the group discussion.

### ***3.12.1 Focus group topic guide***

The focus group interviews were designed to check my interpretation of the data from the individual interviews and were conducted accordingly, using a topic guide covering the key themes emerging from the data, described below and attached at Appendix 15. I summarised the main findings, one theme at a time and discussion of each theme was encouraged. No new data emerged in terms of healthcare service access issues, disclosure management, relationships with healthcare staff, or self-management of health conditions, although the original findings were confirmed with similar participant reports. In discussing potential solutions, those already suggested by the individual interviewees were highlighted for comments and focus group participants were invited to make further suggestions. This allowed more detailed discussion of the suggestions already received and resulted in some

additional ideas to help address the range of issues reportedly experienced by people with low literacy.

During the focus group discussions of potential service solutions, I introduced the topic of Ask Me 3<sup>171</sup> and Teach-back<sup>172</sup> as potential ways of addressing the expressed desire for simple explanations. The suggestion to implement these practices did not emerge from the participant interviews. It is unlikely that participants would have knowledge of these methods, which originated in the US and are not widely used in this country. I explained the systems to the groups. Ask Me 3 involves the patient asking the clinician the following three questions, designed to ensure that the patient is given the most salient information and advice associated with their diagnosis:

What is my main problem?

What do I need to do?

Why is it important for me to do this?<sup>171</sup>

The Teach-back method involves the clinician checking that the patient has understood the diagnosis and instructions for self-care they have just received. It recommends that the clinician does not ask the patient directly if they have understood but asks the patient to explain or demonstrate what they have been told, implying responsibility for giving the instructions rather than focusing on the patient's ability to understand. Questions such as *"I want you to explain to me how you will take your medication, so I can be sure I have explained everything correctly,"* or *"Please show me how you will use the asthma inhaler, so I can be sure I have given you clear instructions"* are suggested in implementing this method.<sup>172</sup>

### ***3.13 Data processing and analysis***

#### ***3.13.1 Handling the data***

Interviews were digitally recorded and were transcribed verbatim and produced as Microsoft Word documents. The funding granted by the CSO provided for transcription of the interviews to be carried out by TP Transcription Services, a company based in Wales but also trading on the internet (<http://www.uk-transcription.co.uk/about.htm>) I transcribed 4 interviews initially to immerse myself in the data and begin the process of analysis. For the remaining individual and focus group interviews, sound files taken from the digital recorder were sent to TP Transcription Services. Independent transcription offered the considerable advantage of time and I was fortunate to gain funding for this to be done. However, the disadvantage in interview material being transcribed by someone other than the interviewer means a potential loss of valuable material which can add to the findings. In order to mitigate the potential effects of such an arrangement, when transcribed files were returned to me I added a final step to the process of transferring the interview material to a text document for analysis. I read through each transcript, listening to each interview sound file alongside it, checking accuracy and noting any relevant aspects of the interview in two ways. First, noting, from the sound material, points where something had been said in a particular manner, such as in a jocular way or when the participant had expressed particular emotion. My having carried out the interview helped to confirm these points in the recorded conversation. Second, noting points of interest that I had recorded as field notes immediately after the interview, such as when the participant had shown signs of distress or displayed body language or gestures which added to the sentiment of the recorded words. In this way, I arrived at the complete data set to be analysed.

### **3.13.2 Analysing the data**

The analysis of qualitative interview data is set, not at the level of differences or similarities in people's answers to the same set of questions, but at a conceptual level, inductively generated through the data. Interpretive themes on which to construct analyses and argument are ascertained.<sup>152</sup> Three different contexts of interpretation have been identified in qualitative analysis: self-understanding which involves the researcher formulating what the participants mean and understand; critical common sense understanding, whereby statements of participants are placed in a wider arena according to the researcher's knowledge about the contexts of these statements; and theoretical understanding, which places the interpretation in a broader theoretical perspective.<sup>173</sup> This fits with the iterative process described by Ritchie and Lewis in their general depiction of the analytical process. They offered an analytical hierarchy, presented as a ladder of steps moving from raw data through the data management and labelling process to descriptive accounts and then explanatory accounts. They emphasised the building block approach which allows moving back down the ladder as well as continuing to move up towards the more abstract, theoretical analysis.<sup>153</sup> The approach thus described they related to thematic, cross-sectional analysis based on interpretations of meaning<sup>153</sup> which provided a suitable structure on which to base the analysis of the interview transcripts and field notes which formed the data set of this study. This fitted with the use of Framework,<sup>174</sup> a matrix based method for ordering and synthesising data which Ritchie and Lewis implemented in describing the process of moving through the analytical hierarchy.<sup>153</sup>

### **3.13.3 Framework analysis**

Framework analysis<sup>174</sup> was the preferred method of data analysis for several reasons. First, it is particularly suited to conducting applied qualitative research. Applied research unlike basic or theoretical research is often required to meet specific informational needs, to provide a greater understanding of the issues addressed, to provide answers and to suggest

strategies to effect outcomes. Second, Framework analysis provides a visible method, which, can be viewed, reconsidered and reworked because the analysis follows a well-defined procedure, which is documented and accessible. Although, the process is systematic and disciplined, it still relies on the creative and conceptual ability of the analyst to determine meaning, salience and connections.

Framework has recently become available as a Computer Assisted Qualitative Data Analysis Software (CAQDAS) package and I undertook a month's free trial of the software. While I acknowledged the advantages of such a package, I preferred manually working with the transcripts, coding and recoding on paper. I felt more able to immerse myself in the data and work with the data set in this way. I then used Microsoft Word which allowed for searching and locating words and phrases within and across individual interviews and Microsoft Excel which provided a spreadsheet to organise the data for analysis. This meant that part of the process benefited from the use of software in terms of ease of putting relevant data together but the conceptualisation and coding remained as manual processes.

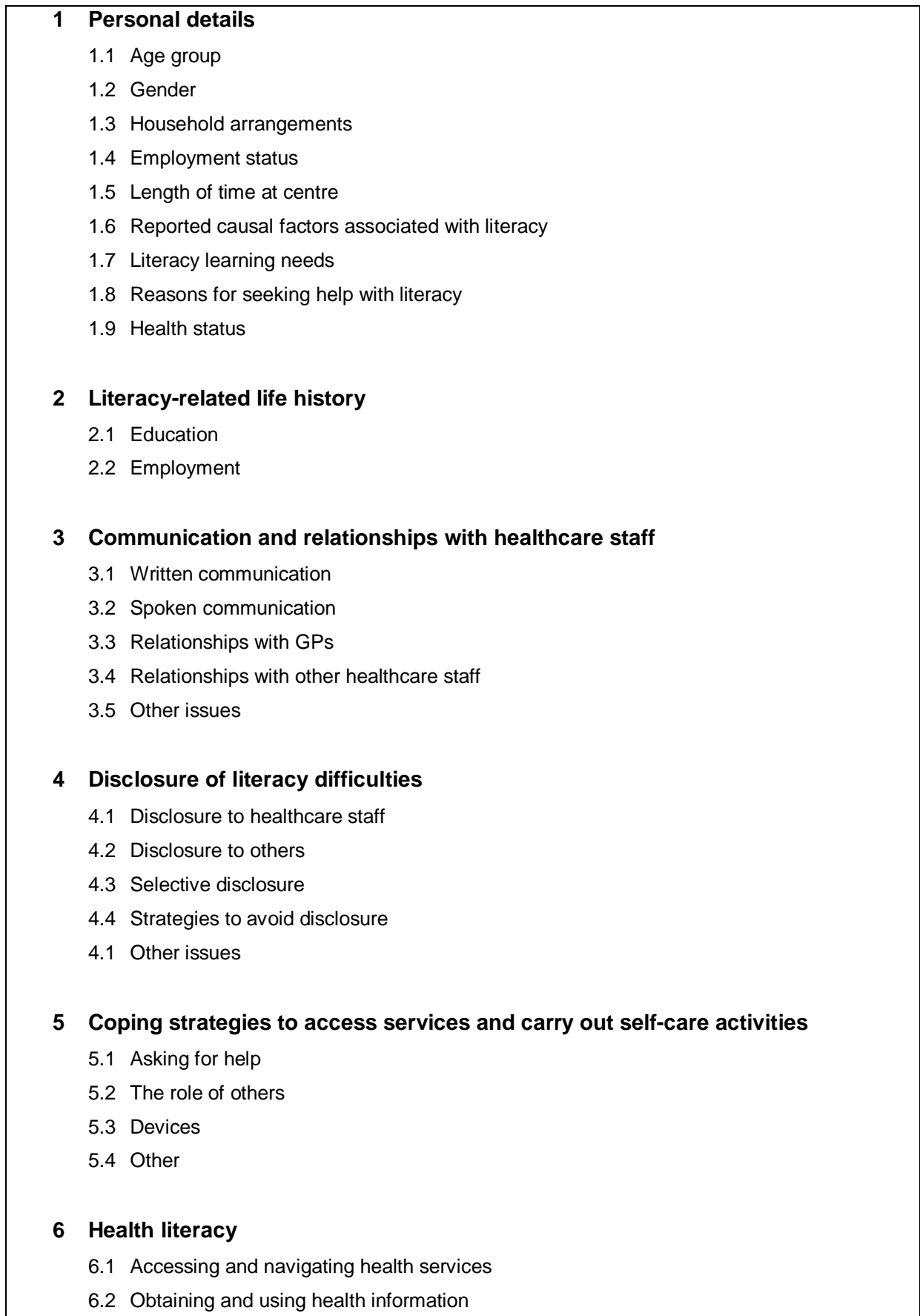
The thematic framework is the central component of the Framework method, within which data are classified and organised according to key themes, concepts and emergent categories. Each study therefore has a distinctive thematic framework which evolves and is refined through familiarisation with the data and cross-sectional labelling.<sup>153</sup> I set out to follow the steps advocated in the use of Framework as an analytical tool and demonstrated by Ritchie and Lewis.<sup>153</sup> There follows a description of each stage of the analysis which I began by familiarising myself with the 'raw' data, an activity described as "*crucial*" at the start of the analysis to build a foundation for what follows.<sup>153</sup>

### **3.13.3.1 Familiarisation**

As already described, I transcribed 4 interviews initially and I read the transcripts of the remaining interviews while listening to the sound files. It has been suggested that during the familiarisation process, only a selection of the data need be read or listened to.<sup>153</sup> While it was time-consuming to go through the whole data set, it had its advantages. I was able to correct inaccuracies in transcription right away and this was important in the transcripts of some of the participants who had strong Scottish accents. Having the transcription done elsewhere meant that I had saved many hours of work but taking the (much shorter) time to check the transcripts helped me to re-engage with the data that I had generated through the interview process. I was also able to identify recurring themes as a preliminary stage of devising a conceptual framework. At this and at each stage of the analysis, transcripts were shared with my supervisors so that we could discuss emerging ideas and issues throughout the process.

### **3.13.3.2 Identifying initial themes or concepts**

After listening to and checking the transcripts, the next stage was to draw up a list of themes and ideas. Once this had been done, the next step was to devise an index, or conceptual framework<sup>153</sup> which had a hierarchy of main and subthemes. As advocated by Ritchie and Lewis,<sup>153</sup> each of the main themes included an 'Other issues' category to allow for any uncovered areas emerging within the broad subject areas.

**Figure 4: Conceptual framework for findings from participant interviews**



6.3 Knowledge and understanding of health conditions and treatment

6.4 Other issues

## **7 Mental wellbeing**

7.1 General mental wellbeing

7.2 Problem attribution

7.3 Stigma

7.4 Stress

7.5 Confidence

7.6 Social experiences

7.7 Other

## **8 Suggested changes to health service**

8.1 Written communication

8.2 Spoken communication

8.3 Hospital environment

8.4 Awareness and acknowledgement of low literacy

8.5 Facilitating disclosure of low literacy

8.6 Avoiding disclosure of low literacy

8.7 Other issues

The next task was to apply the initial conceptual framework to the interview transcripts. Ritchie and Lewis refer to this stage as 'indexing' but some others call this 'coding.' The former term is preferred as one which depicts the process of viewing the categories according to the way in which they fit the data rather than the latter which suggests capturing dimensions or content which has already been more precisely defined and labelled and may not be intended or appropriate at an early stage of analysis.<sup>153</sup> Transcripts were labelled according to the categories within the index as described next.

### ***3.13.3.3 Labelling and sorting the data by theme or concept***

The data were labelled in two stages as I felt this made the later sorting easier. The first stage was to label the data according to the main themes shown in the index above.(Figure 4) Transcripts were printed with line numbers and a wide margin on one side to allow for

notes on particular categories. Coloured highlighter pens were used to mark words, phrases and sections which were associated with the particular main theme index terms. This exercise was carried out across all of the printed transcripts. Some sections were indexed to more than one main theme. For example, the short passage illustrated below (Figure 5) was categorised as Disclosure; Coping strategies to access services and carry out self-care activities; and Health literacy.

**Figure 5: Example of multiple themes**

**INT1**

77 **Katy:** Most of the time well I'll go to the chemist and just  
 78 get it on Direct Care so I know I'm getting the right stuff but  
 79 ken, like if you're somewhere else you're only allowed one  
 80 chemist for Direct Care so then you've just got to guess or  
 81 ask somebody but you don't want to say "By the way, which  
 82 one is Calpol?" You know? (laughing)

When the transcripts had been coloured to indicate the length of section to which each index category applied, these were used as a reference to cut and paste the relevant sections into a separate document for each index category. Ritchie and Lewis warn of the danger of the 'cut and paste' method leading to loss of context or location of the material.<sup>153</sup> To guard against this, I documented the interview name and number and the line numbers of each of the extracted sections and at this point did not cut them too finely to the words or phrases to which the index applied. For example, I included a sentence containing a particular phrase rather than the phrase alone. A set of files was thus produced, with individual files containing all of the extracts categorised under a particular main theme. To illustrate this, Figure 6 shows some extracts from the Microsoft Word file containing data on disclosure. As can be seen from this example, references to many aspects of disclosure were included.

**Figure 6: Extracts from data file: Disclosure of low literacy****INT 2**

310-346 **Ralph:** ..most people can read and write and stuff but if you was to put it across the board, it would look less of a stigma. If everybody's got it rather than if nobody's got it, you know just certain people that's got it but I also feel that... I also feel that if the doctors have got your notes and there's something in your ... just a little something in your notes saying that you find it difficult with this that and the other, it makes it easier for you then to... to speak to you in a certain way. Cos my dyslexia is not noted in the notes.

**Interviewer:** Would you want it to be?

**Ralph:** Um, it would be my own, personal choice, it would be the person's personal choice whether they would want that, you know what I mean, or not so the nurse should ask at the beginning you know, do you want us to put a little wee note in, in your... it doesn't have to be like majorly like, you know, just saying this person finds it a little bit difficult with reading and writing. 'Could you give them extra help or extra help with understanding,' that's what it should say, it doesn't specifically... it's not a specific thing. It just says you need extra help.

**INT 7**

242-247 **Karen:** My dad's got dyslexia and when my dad was younger, there wasn't the help that there is now and everything and he got shoved to the back of his class and he got treated differently so I don't know if it's because of all the stories that I've heard from him that have thingied my back, I don't know.

**INT 16**

311-318 **Louise:** I think if it was in with what they were asking you, I think it would be easier for you to actually say, yeah, I have difficulty with the spelling or I'm not very good at, if it was brought to you, them saying it to you rather than you having to say. If they were more aware that people do have the difficulty, maybe it would be easier for me to say to them, yeah, I do have because people don't really bring it up, you won't mention it.

334-338 **Louise:** I wouldn't like my own friends to know. If it did come up medically, I think I would say. I have had to say, when I was doing the [job], I had to tell the [governing body] because I had lots of paperwork to do and I couldn't keep up with it.

**INT 18**

186-188 **Sandie:** I'd ask for help, I don't mind if they think oh she's being a bit stupid or a bit thick, I am just like well I need to understand it.

**INT 21**

444-449 **Bert:** It is embarrassing so you know you should have done it when you were younger but you feel ashamed and feel embarrassed, you don't want people to laugh at you as you become an adult, you don't want people to laugh at you and making fun of you. It like knocks you back, you know, and it's all these things.

The individual Microsoft Word documents were then printed with a wide margin on one side to allow for the second stage of labelling which was to categorise the data according to subthemes. Again, this was done manually using coloured highlighter pens and some of the extracts covered more than one subtheme. For example, extracts from Interviews 1 and 12, illustrated in Figure 7 below both refer to the more than one category within Disclosure: Disclosure to healthcare staff; and Strategies to avoid disclosure. The interview 1 extract was also labelled with a third category, that of Selective disclosure.

**Figure 7: Overlapping aspects of disclosure****INT 1**

109-121 **Katy:** My doctor knows, my doctor's been my GP since I was born. He's all right, but he's off quite a lot just now so he's got locums in and they just speak to you as if you know what they're on about.

**Interviewer:** Yeah?

**Katy:** I just sit there and nod, like, yeah, yeah, OK

**INT 12**

**Carol:** When I had [daughter] I had to fill out the sheets, like when she had a wet nappy and stuff, that was quite hard and I never told anyone, but I did find it quite hard. I just had to get my sister to help us with it. I found it really hard, like reading stuff and that.

Once labelled, the data were ready to be sorted and synthesised according to the indexed subthemes. This was done by drawing up charts, as described next. It should be noted that each stage was part of an iterative process so that if, at any point, new themes or ideas

emerged, I returned to the whole data set or to previous stages of the process as appropriate to fully explore these.

#### **3.13.3.4 *Thematic charting***

Charts were created in Microsoft Excel. A worksheet was designated for each of the main themes. Each interviewee was assigned a row and each of the index subthemes a separate column. The participant column, with interview number and pseudonym displayed, was included, in the same order, in each worksheet to allow for merging of data from different worksheets if needed. This was done, for example, when the Health Status column from the Personal Details chart was cut and pasted into the Health Literacy chart also so that health literacy issues could be examined in the context of what health problems or conditions each participant had reported.

Charting in this way begins the process of distilling the essence of the evidence for later representation.<sup>153</sup> Three requirements to retain the essence of the original material<sup>153</sup> were observed at this stage of the analysis. These were: the retention, as far as possible, of the participants' own language; interpretation kept to a minimum to allow the original expression to be revisited; and the inclusion of material for which relevance may not be immediately clear.

Summaries were therefore made in the terms used by participants, relevant line numbers from the transcripts were included to allow checking of the original words, and an asterisk marked where quotations were felt to be salient to the points being categorised. As already mentioned, the relevance of sections of data often emerged as the process went on, so that transcripts were revisited as part of the iteration of the assignment to themes and sub-themes. Figure 8 shows a brief extract of the thematic chart for Mental wellbeing. Chart headings replicated the index and were numbered to match categories but as further development of the themes occurred, subthemes and so, columns, were added. For example, in Figure 8 below, the general mental wellbeing category was later split into new

categories such as improved mental wellbeing associated with adult learning, as the first two entries in Interview 4 show.

The charting of the data in this way allowed for the next stage of vertical (across the participant sample) and horizontal (for individual participants) analysis.

### ***3.13.3.5 Mapping and interpretation***

Unpacking the content of a particular theme using Framework analysis is done in 3 key stages according to Ritchie and Lewis. These are: detection, in which the substantive content and dimensions of the theme are identified; categorisation, which involves refining categories and assigning descriptive data to them; and classification in which groups of categories are classified at a higher level of abstraction.<sup>153</sup>

Within the thematic charts, each column was examined and different elements, constructs and categories identified. Again this was done manually, using coloured highlighter pens on the printed worksheet charts. Data were sometimes re-categorised at this stage or new data added. The resulting data were grouped into new categories within the relevant subthemes so that similar reported experiences or attitudes, for example were grouped together to provide a new descriptive category. This stage is still required to remain close to the data and it has been suggested that a useful test of this would be whether this initial categorisation would still be recognised by the study participants.<sup>153</sup>

**Figure 8: Thematic chart for mental wellbeing**

<b>Interview no. and pseudonym</b>	<b>General mental wellbeing (7.1)</b>	<b>Problem attribution (7.2)</b>	<b>Stigma (7.3)</b>
<b>INT4 Margaret</b>	Wants to learn and study everything now, doesn't have to cheat and not tell the truth any more (83) Doesn't think she's stupid now (138) Told tutor she didn't think she was thick and didn't want to be talked to as if she was thick (329) Felt hurt when dyslexia diagnosed. Suspects father dyslexic. Didn't have caring mother (458) Doesn't want people to get one over on her - doesn't think that's the dyslexia (494) Would have been put in a mental home years ago (629) Regrets not doing it earlier would have liked to be a teacher.	NHS not geared up for dyslexia (527) At first thought it was her fault people belittled her, now other people's ignorance. (424) Wouldn't listen to it now (438)	Mum told her not to bother about dyslexia because detriment against you That stuck in her mind *(483) Not brainy enough like some other people (493)
<b>INT5 Stevie</b>	Can't remember things for long or doesn't take things in, pretends to have heard(113) Had nervous breakdown due to family bereavements (141) Panics if has to use phone Feels he can't get his point across(234) Wife and her family support him a lot. Panics if he thinks he hasn't got enough tablets left (261)	Embarrassed, terrible he can't read at his age, his fault, should have stuck to education (542)	Embarrassed people would think he doesn't want to read or can't read (522) Embarrassed to ask for help (530)

### **3.13.3.6 Establishing typologies**

Developing a typology involves cross-case analysis so that dimensions on which the study population divides are identified.<sup>153</sup> Participants' reported attitudes to disclosure of their low literacy and the apparent association with many reported experiences, beliefs and feelings emerged as such a dimension. This was tested across the sample to see if each case fitted into a single typology. Initially there appeared to be 4 potential categories: Revealers; Restrictors; Constrainers and Concealers. These categories were created to describe the range of reported attitudes to disclosure, these being: willing to reveal their low literacy to everyone; disclosure of low literacy restricted to some but not others; disclosure of low literacy constrained by circumstances such as finding it difficult to bring the subject up; and unwilling to reveal low literacy to anyone, respectively. In assigning cases to one of the 4 categories, it proved problematic to fit all cases into one and only one category, as recommended.<sup>153</sup> In discussion with my supervisors, it was agreed that the categories of Restrictors and Constrainers were not necessarily mutually exclusive. I had moved cases between the two in attempting to categorise them and there was an argument for the possibility that participants who reported being constrained in revealing their low literacy also disclosed selectively at times and similarly, those who reported selective disclosure possibly did so at times because of particular constraints. This led to the decision to assign to three categories, combining the Restrictors and Constrainers into one group of Limiters. It is recommended that typologies should not be created for their own sake but that they should help to explain differences rather than be a purely conceptual exercise.<sup>153</sup> The reduction to three categories in this case proved to be appropriate in that the Limiters formed a cohesive category in examining the data to present explanatory accounts.

### **3.13.3.7 Explanatory accounts**

The later stages of the analysis involved finding associations between the themes for particular participants and across cases, exploring common themes and categories to



provide explanations for the findings. This process was influenced by both the original research questions and by the themes that had emerged from the data. These two viewpoints merged to provide a picture of the social reality of those with low literacy. The research questions focused on experiences and issues in relation to health and situations such as access to health services and performing self-care activities. The emerging theme of mental wellbeing and stigma in particular added to the potential impact on health itself but in the later stages of analysis, it became clear that the latter themes were also very much related to the data answering the wider aspects of the research questions and it was the combination of these that provided explanatory accounts.

The findings thus generated were the result of an iterative process which allowed transparency and documentation of each of the analytical steps, contributing to the rigour of the study.

### ***3.14 Conclusion to this chapter***

The process described in this chapter produced a rich data set which helped to generate knowledge on a range of issues beyond that initially anticipated with the first draft of the topic guide. Two findings chapters follow. Before these are presented, the significant role of stigma in participant accounts and its effect on many aspects of health, healthcare and self-care warrants an introduction. The next chapter is thus a brief description of stigma and the body of research which has contributed to the development of the concept. This is included to aid understanding of some of the concepts introduced in the findings chapters which follow on from there.

A summary of the preliminary findings of the primary research was published by the CSO in July 2010 (Appendix 16).

## **Chapter 4: Concepts of stigma and its role in social relations**

### ***4.1 Chapter Overview***

This is a very brief chapter to introduce the early and more recent concepts of stigma, which include recognition of its role in a social context. Conceptually, stigma has been developed from the view of it as an attribute attached to an individual to a co-occurrence of several aspects of social relations. The chapter is included at this point because the focus on stigma arose from the research process and early findings rather than as an aspect which it was originally planned to explore in-depth.

*“An individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us”*

Erving Goffman<sup>175</sup>

## **4.2 Introduction**

In my introduction to literacy and issues associated with low literacy (Chapter 1), I postulated that stigma and its subsequent effects may be felt or experienced by people with low literacy. I suggested that this may affect people's confidence or self-esteem and thereby their ability to function in the healthcare environment. The individual interviews brought this issue very much to the fore and, as the analysis progressed, it became apparent that stigma associated with low literacy played a major role in the behaviours and experiences of participants in relation to health, both in terms of their own mental health and wellbeing and in their relationships with healthcare staff. I therefore provide here an introduction to the concept of stigma, describing how that concept has evolved over time, and how an understanding of its role in discrimination within society and in relationships between stigmatised and non stigmatised individuals has been recognised and developed in the literature.

## **4.3 Stigma as an attribute**

Erving Goffman, in his seminal 1963 work: *Stigma: Notes on the Management of Spoiled Identity*,<sup>175</sup> defined stigma as “an attribute that is deeply discrediting” and proposed that someone who bears a stigma is “reduced in our minds from a whole person to a tainted discounted one.” Stigma is the process by which the reaction of others spoils *normal identity*. Goffman argued that the social interaction between two people, one of whom has a deeply degrading stigma will tend not to go smoothly, adding that the presence of the stigma would be expected to influence the perceptions and feelings of both individuals and their interpersonal behaviours.<sup>175</sup>

In spite of his description of stigma as an attribute, for Goffman, stigma was very much a process based on social relationships and social construction of identity, rather than something that was attached to an individual.<sup>175</sup> However, since the 1960s a considerable body of research and discussion, which has drawn on Goffman's work, has emerged, much

of which has focused on the stigmatised individual and the negative attributes attached to individuals.<sup>176, 177</sup>

Goffman's psychological and social elements of the concept of stigma have been primarily used in analysis of psychological impact of stigma on individuals.<sup>177</sup> This has created an understanding of how stigma is internalised and shapes individual behaviour but questions about how social life and relationships are changed by stigma have been largely neglected.<sup>176</sup> Parker and Aggleton suggested that the emphasis placed by Goffman led to a focus on stigma as if it were a kind of thing, ( a cultural or individual value) a relatively static characteristic or feature albeit one that is at some level culturally constructed. Thus stigma has been interpreted and understood as a negative attribute and mapped onto people who by virtue of their differences are understood to be negatively valued in society, disregarding Goffman's concern with issues of social change and social construction.<sup>175</sup>

#### **4.4 Stigma as social identity**

The social context of stigma was demonstrated by Goffman in his description of an individual as having two identities. These were: a "*virtual social identity*," an identity characterised by the attributes others assume to be possessed by that individual; and an "*actual social identity*," characterised by the actual attributes possessed by the individual, the stigmatising attribute being the discrepancy between these two identities.<sup>175</sup> Goffman further offered two positions related to the visibility of a stigma: the first, when the stigmatised individual assumes his differentness is known about already or is evident on the spot, in which case the individual is "*discredited*;" the second, where the stigmatised individual assumes his differentness is not known about by those present nor immediately perceivable by them, in which case the individual is "*discreditable*." He suggested that, although there is an important difference between these two situations, stigmatised individuals are likely to have experienced both.<sup>175</sup>

Some stigmatising conditions, such as physical disfigurement are immediately obvious to those involved in a social encounter with the individual, while others, such as positive HIV status are not, and may remain concealed in most social contexts. Having such hidden traits or attributes, discreditable to one's personal identity was conceptualised as having "*stigma potential*" by Schneider and Conrad. The "*potential*" exists in the context of the knowledge about one's condition being limited to relatively few others and that if it were to become more widely known, significant redefinition of self accompanied by various restrictions and regulation of conduct might well follow.<sup>178</sup>

Related to these concepts, stigma can be "*felt*," which refers to the shame associated with the condition and the fear of discrimination; or "*enacted*," which refers to episodes of actual discrimination against an individual with the stigmatising condition, solely on the grounds of their social unacceptability.<sup>175</sup> Jacoby, in her study of people with epilepsy in remission, illustrated the distinction between these two perspectives. Using a scoring system, she reported that individuals labelled as epileptic continued to feel stigmatised, even after their seizures were in remission.<sup>179</sup> Several authors have suggested that felt stigma can be learned from others

Schneider and Conrad highlighted that people learn to be discreditable from significant and supportive others, particularly parents. In their qualitative study of people diagnosed with epilepsy, they highlighted the role of parents in "*training their children in the stigma of epilepsy*," describing these parents as "*stigma coaches*." They also pointed out those diagnosed as adults experienced "*stigma coaching*" from others around them.<sup>178</sup> Similarly Scambler and Hopkins reported that most of the participants they studied did not feel stigma because of experiencing discrimination but that felt stigma most often was the product of stigma coaching.<sup>180</sup> Others have reported similar effects, for example Joachim and Acorn suggested that parents who instruct their children to hide a disability will probably raise children who go to great lengths not to disclose.<sup>181</sup>

In these broader, more social views and concepts of stigma which have emerged and have been more predominantly documented since the 1990s, discrimination has been an important feature.

#### **4.5 Stigma and discrimination**

Various conceptual models have pointed to different understandings of where responsibility lies for 'the problem' along with different prescriptions for action and Sayce emphasised that there was a growing body of literature on discrimination, which she proposed as a more promising model on which to base social change.<sup>182</sup> Sayce examined the limitations of the concept of stigma and how it was applied, with particular reference to users of mental health services, and pointed out that, whereas stigma attaches to the individual, discrimination results from the action of others.<sup>182</sup> She argued that the mark of shame should reside not with the individual who has been stigmatised but with those who behave unjustly towards her or him, claiming that *"terms such as stigma render the act of unfair treatment invisible."*<sup>182</sup>

The emphasis on discrimination and the social context of stigmatisation processes resonated with the Social Model of Disability which had been espoused by activists in the 1970s and developed by academics in the 1980s and 1990s. The main assertion of the Social Model of Disability is that people may have impairments but their disability is socially constructed, forming institutionalised barriers to participation for those with impairments.<sup>56</sup>

Oliver, a leading researcher and long time advocate of the Social Model of Disability, argued that disabled people had not found stigma to be a useful concept because it has been unable *"to throw off the shackles of the individualistic approach to disability with its focus on the discredited and the discreditable."*<sup>183</sup> This view emphasised Oliver's perception, also expressed by others, that the legacy of Goffman's<sup>175</sup> work had focused stigma on individual self perception and micro-level interpersonal interactions, rather than widespread and

patterned exclusion from economic and social life,<sup>183</sup> which has been the focus of more recent developments.

#### **4.6 Stigma and social interaction**

The concept of stigma has been developed further to include cognitive and behavioural elements on the part of the stigmatised and the stigmatiser and in 2001, Link and Phelan proposed a model which placed stigma firmly in a social context and embraced the notion of discrimination, acknowledging the contribution of the Social Model of Disability to this stance.<sup>184</sup> They aligned themselves with Goffman's original definition and conceptualisation of a virtual social identity,<sup>175</sup> by describing stigma as an attribute, behaviour or reputation which is socially discrediting in a particular way, and posited that, at first appearance of someone in a social situation, the anticipated social identity leads to normative expectations.

Link and Phelan further proposed that stigma is the co-occurrence of labelling, stereotyping, separation, low status and discrimination and that stigmatisation is "*entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination.*"<sup>184</sup> The relevant steps considered within this conceptual model were:

1. Individuals distinguish and label human differences
2. Dominant cultural beliefs link those labelled persons to undesirable characteristics that form a stereotype.
3. Labelled individuals are placed in distinct categories so as to accomplish some degree of separation of "us" from "them"
4. Labelled individuals experience status loss and discrimination that lead to unequal outcomes.<sup>184</sup>



Link and Phelan emphasised their use of the word 'label' rather than 'attribute', 'condition' or 'mark' in these descriptions of how stigma comes about, claiming that the latter terms locate the thing that is being referred to in the stigmatised person and risks obscuring the social processes involved in producing stigma.<sup>184</sup> They described the immediate consequence of successful negative labelling as a general downward placement of a person in a status hierarchy, postulating that the person is connected to undesirable characteristics that reduce his or her status in the eyes of the stigmatiser.<sup>184</sup> Again, this resonates with Goffman's description of someone becoming *discredited*. Goffman, in referring to reduced status in a social context, suggested that the stigmatised individual is one who might have been easily accepted in social circumstances but the trait that he possesses, if obvious or revealed, turns people away, "*breaking the claim*" his other attributes have on those around him.<sup>175</sup> The individual who is likely to be negatively labelled should the stigma be revealed, may take steps to cope with the stigma, or more specifically, to hide it.

#### **4.7 Coping with stigma**

Information control is particularly important to the individual who has a potentially stigmatising attribute. The individual may need to decide how to deal with the information that can lead to being discredited, to tell or not to tell.<sup>175</sup> Disclosing a stigmatising condition may lead to increased support but it carries with it the threat of being stigmatised and therefore discredited. The person may therefore make the decision to ensure no one knows and so may cope by what Goffman described as "*passing*" and/or "*covering*." "*Passing*" involves deliberate concealment of the stigmatising condition. The goal is to become part of a group of "*normals*," as Goffman describes non-stigmatised individuals. Potential strategies include obliterating signs, or compartmentalising the world into the large segment that knows nothing about the condition and the very small support group of individuals who are confidentially notified.<sup>175</sup> People may use "*disidentifiers*" to pass as normal, and Goffman gives the example of illiterates wearing 'intellectual' glasses.<sup>175</sup>

“Covering” has the intent of downplaying rather than concealing the condition, such as displacing the stigma to a lesser condition e.g. pretending to be temporarily stigmatised or “*minimising the obtrusiveness of their stigma*,” for example, bad spellers writing incomprehensibly, so that their incorrect spelling is not revealed and their apparent poor writing is viewed by others as a less stigmatising condition.<sup>175</sup>

The management of information regarding a potentially stigmatising condition can be a potent source of stress and anxiety.<sup>179</sup> A person who successfully passes may become part of a normal group but they run the risk of being caught in a lie and having to account to people. Therefore, both revealing and concealing a condition can be associated with stress. While disclosing the condition might reveal information that can be discrediting, passing can be stressful because of the worry about the risk of discovery and the embarrassment of being caught.<sup>175</sup> The risks therein include being rejected and stigmatised; having difficulty handling the responses of others; and losing control.<sup>181</sup> Other associations between stigma and mental wellbeing have been suggested.

#### **4.8 Stigma and mental wellbeing**

Implications for the social and mental wellbeing of stigmatised individuals have been demonstrated. Participants who scored positively on a stigma scale were reported to have lower mean scores for self esteem and mastery and higher mean scores for energy, emotional reaction and social isolation<sup>179</sup> Stigma has also been considered to account for inequalities in life chances and outcomes. The extent to which a stigmatised person is denied positive life experiences and suffers more negative life experiences has been suggested as a source of chronic stress with consequent negative effects on mental and physical health.<sup>185</sup>

Link and Phelan pointed out that the impact of stigma was underestimated because research tended to focus on one outcome. They expressed the belief that stigma could be shown to

have an enormous impact on people's lives if all stigmatised conditions and all outcomes were considered together. In order to substantiate this idea, they analysed nationally representative data from the US, taking into account multiple stigmatising factors in relation to self-esteem. They reported that stigma could explain a full 20% of the variance beyond the effects of age, sex and years of education.<sup>186</sup>

Unequal outcomes were purported to be associated with status loss, discrimination, rejection and exclusion in the Link and Phelan conceptual model of stigma,<sup>184</sup> and these unequal outcomes may be experienced in terms of physical health. Wilkinson, a lead researcher in the field of health inequalities, postulated that the direct effects of subordinate social status, as opposed to the effects of poorer material circumstances, exert a strong negative influence on health and contribute to health inequalities.<sup>187</sup> These effects have been confirmed by evidence that subordinate monkeys and low-status humans demonstrate differences in health factors, including faster build-up of atherosclerotic plaque in their coronary arteries; higher likelihood of suffering from central obesity; potentially more damaging levels of blood fats; and raised stress levels.<sup>187</sup>

## ***4.9 Conclusion to this chapter***

This chapter was included to introduce the evolving concepts of stigma and its role in social relations. It was included to aid understanding of some of the concepts introduced in the findings contained in the next two chapters.

## **Chapter 5: Living with low literacy: stigma and its impact on social and mental wellbeing**

### ***5.1 Chapter Overview***

In this chapter, the participant sample is described and the findings from the individual and focus group interviews are presented. Participants reported having experienced from an early age, labelling and separation from their peers associated with their low literacy, due to both their own feelings of being different and to the attitudes and actions of others. Reports of participants' experiences at school, in the workplace and in social settings are examined and findings that suggest that these have had an impact on their social and mental wellbeing are presented.

Participants indicated that they attributed their attitudes and feelings about disclosure of their low literacy and their anticipation of stigmatisation to their childhood experiences and influences. The participant accounts of situations and experiences in adulthood provided a picture of continued fear of stigmatisation. Participants as adults reported exercising what appeared to be a greater degree of control of the information regarding their low literacy compared with the fairly general exposure of their low literacy they reported having experienced in childhood. Nevertheless, information control and the avoidance of stigmatisation brought its own stresses and effects on mental wellbeing. The picture presented by most participants was therefore one of their low literacy having had a negative impact from an early age, and one which continued into adulthood.

*“I – am – in – the - slow  
 read – ers – group – my - brother  
 er – is – in - the – foot  
 ball – team – my – sis - ter  
 is – a – ser - ver - my  
 lit – tle – broth – er - was  
 a – wise – man – in - the  
 in – fants – Christ –mas - play  
 I – am – in – the - slow  
 read – ers – group – that - is  
 all – I – am – in – I  
  
 hate - it.”*

Allan Ahlberg <sup>188</sup>

## **5.2 Introduction**

In accordance with my ontological and epistemological beliefs, laid out Chapter 3, I carried out individual semi-structured in-depth interviews with 25 participants with low literacy. Twenty four participants were identified through their attendance at Dundee City Council Adult Learning Centre where they were enrolled as adult learners and one through Dundee Healthy Living Initiative. Two focus groups, consisting of 9 participants, 5 of whom had been interviewed individually and 4 of whom were new to the study, were carried out as a means of checking and confirming the interpretation of the findings from the individual interviews. All focus group participants were recruited through Dundee City Council Adult Learning Centre. This gave an overall sample of 29 participants consisting of both genders: 19 females and 10 males; and a broad age range: 17-59 years.

Stage of literacy learning varied across the sample. Some participants were relatively new to adult literacy classes, having begun very recently or within the previous year, while others had attended for a number of years. Frequency of attendance each week also varied across the participant sample. Some reported attending more than once a week while others had to fit their attendance in around shift work or irregular working hours.

It should be noted at this point that the social practice view of literacy embraces the notion of multiple literacies and in this and in adult education, the term 'literacies' tends to be used rather than 'literacy.' Throughout the findings and discussion chapters I have stuck with 'literacy' in keeping with the earlier use of the phrase 'functional or health literacy.' I have used the generic term 'low literacy' to describe participants' learning needs although these vary widely across the participant sample and frequently incorporate multiple literacies.

Those recruited thus provided an appropriately broad sample to generate data to help provide answers to the research questions.

### ***5.3 Individual interview participant profile***

Eighteen females and seven males aged from 17-59 participated in one-to-one semi-structured interviews. The majority of participants were unemployed at the time of interview. Those who were employed or had been in employment mainly worked in manual or unskilled jobs. Some were employed in areas such as social care, where the need for literacy activities in the form of information recording and the completion of training courses was reported to have been increasing over recent times, bringing challenges to those entering these areas of work as well as those who had spent several years in these types of employment.

Sixteen of the interviewees were living with one or more long term conditions which required regular primary care and specialist clinical contact as well as self-management activities. Reported long term conditions included asthma, diabetes, fibromyalgia, arthritis, eczema, diverticulitis, anaemia, respiratory problems and mental health problems. Fourteen of the 25 interviewees had had contact with health services through their own or their partner's pregnancy and childbirth. A few participants had had very little experience of contact with health services, but the majority had seen their GP or purchased over the counter medicine either at a pharmacy or a general retail store in the recent past.

The characteristics of the 25 adult learners interviewed individually are summarised in Table 3. Names have been changed and ages grouped into age bands to protect confidentiality.

**Table 3: Summary of key characteristics of interviewees**

<b>Interview no. and pseudonym</b>	<b>Age group</b>	<b>Gender</b>	<b>Employed</b>	<b>Long term condition</b>
INT1 Katy	20s	F	Training for employment	Yes
INT2 Ralph	30s	M	Unable to work due to medical condition; does voluntary work	Yes
INT3 Dorothy	50s	F	No. Unpaid carer	Yes
INT4 Margaret	50s	F	No	Yes
INT5 Stevie	30s	M	No	Yes
INT6 Jack	40s	M	No. Lost job recently	Yes
INT7 Karen	20s	F	Yes	Yes
INT8 Olive	50s	F	No. Unpaid carer until recently	No
INT9 Harry	40s	M	Yes	No
INT10 Megan	teens	F	No	No
INT11 Yvonne	30s	F	Yes	Yes
INT12 Carol	20s	F	No	No
INT13 Cathy	50s	F	No	Yes
INT14 Gordon	50s	M	Yes	No
INT15 Marion	50s	F	No. Training for new job	No
INT16 Louise	40s	F	Yes	No
INT17 Barbara	50s	F	Yes	No
INT18 Sandie	teens	F	Yes	Yes
INT19 Pauline	20s	F	No	Yes
INT20 Moira	40s	F	No. Lost job recently	Yes
INT21 Bert	40s	M	No	Yes
INT22 Debbie	teens	F	Work placement. Training for employment	No
INT23 Carrie	teens	F	No	Yes
INT24 Chloe	20s	F	No	Yes
INT25 Fraser	20s	M	Yes	Yes



### **5.4 Focus group participant profile**

Focus Group 1 consisted of 4 participants (3 previously interviewed and 1 new) and Focus Group 2 had 5 participants (2 previously interviewed and 3 new). Focus group participants were attending the Adult Learning Centre with a variety of literacy learning needs. Unlike the individual interviewees, they were not asked for detailed personal information. The characteristics which were recorded are shown in Table 4. New pseudonyms are presented here for those who had been interviewed previously to ensure that what was discussed in the one-to-one interviews remained confidential.

**Table 4: Focus group participant characteristics**

<b>Focus group</b>	<b>Participants</b>	<b>Gender</b>	<b>Age group</b>
Focus group 1	Evelyn	Female	50s
	Frances	Female	30s
	Jason	Male	20s
	Susan	Female	40s
Focus group 2	Fred	Male	50s
	Iain	Male	50s
	Irene	Female	40s
	Natalie	Female	teens
	Patricia	Female	40s

### **5.5 Findings**

The findings of this study are drawn mainly from the responses of the 25 individual interview participants who gave accounts of their experiences, from which key issues were identified in the analysis. No new data in terms of particular issues for people with low literacy in

answer to the first two research questions were generated by the focus groups. However, the focus group sessions provided opportunities for further discussion of potential service initiatives to address the issues highlighted and these were considered in terms of their suitability and some new suggestions added. The timing of these groups, after all the individual interviews had been completed, made it possible to focus more specifically on the collective views and ideas of the interview participants and this generated more detailed suggestions and proposals for appropriate health service responses, which are reported as such within this chapter.

### ***5.5.1 Participants' perceptions of their own literacy levels***

Participants provided insight into their perceptions of their literacy skills in two ways: through their accounts of what type of help they were seeking at the Adult Learning Centre; and through their descriptions of their engagement in various literacy activities. Their explicit perceptions of their literacy levels often did not match the levels suggested at other times during their interviews.

In discussing the help they were accessing, most participants reported receiving support with a range of literacy learning needs including reading, writing and numeracy and some said that they were there to focus on a particular skill such as punctuation or computer skills. During the course of the interview, participants' learning needs often appeared to be broader than at first suggested. For example, Olive described herself as always having been an avid reader who needed to brush up on her English, but later described literacy activities which suggested her reading had required some improvement, which, in turn, had reportedly been achieved through her literacy learning:

*"..... since doing my English and learning where to put in your commas, etcetera and your full stops, my reading has improved as in, when you're reading a book, I mean, I've always read, I can take in that sentence or that paragraph better because when the full stop's there or your comma's there, I'm reading it. Whereas before, I would*

*maybe read and I'd say, 'That makes rubbish. Can't understand that,' so now.....I use my commas. I wouldn't [previously] use my full stops and stuff like that. That is something I've noticed greatly in the reading and I've told [tutor] that. I says, 'What a difference.' Whether it's a newspaper or whether it's one of my books. Whereas instead of maybe having to go over a sentence three times, I could read it the once because I'm using [punctuation]" (Line 311)*

Moirra associated her poor performance in a multiple choice test with lack of confidence in using the computer although she had used a computer for other tasks. In her account of the situation, however, she demonstrated a poor understanding of the purpose and workings of such a test:

*"It was multiple choice, I still couldn't get it right and the answers were there but, what Head Office wanted was a specific answer. No matter what you choose it would be right, but you have to get the right one." (Line 14)*

Literacy activities were described by some in positive ways and by others in ways that highlighted particular issues for the individual. Stevie spoke positively of reading the newspaper but described a painstaking process:

*"I've got a habit of reading the newspaper and I read it for ages and ages and ages, it's like every word, I don't miss a word out ..... and [wife] says 'Well you've been looking at that paper for an hour'... So I like to read every word and if I miss I go back to the start and start again." (Line 446)*

Similarly, Gordon's claim to be 'quite a good reader' was accompanied by a description which suggested that his understanding was often limited:

*"My reading's quite good but what I do have to do .... when you come to a paragraph where it's a novel - I read novels and I read some autobiographies too, to read a paragraph and it's probably just sort of not taking in words, sometimes you*

*understand a sentence and a couple of words - that's fine. If you don't it's a case of having to skip out the bits and pieces that I'm not..... and if it's a paragraph it's really gobbledygook.”* (Line 46)

These two examples warranted consideration in view of my assumption, mentioned in Chapter 3, that participants would consider their literacy levels to be a problem. Both of these men acknowledged limitations in speaking of their literacy activities, but they did not highlight these as a problem for them. Others pointed out the limitations of their literacy activities more specifically:

*“I read books but then it's kids' books so it's quite easy to read.”* (Karen, line 18)

and some participants mentioned literacy activities within social practices which posed problems for them. For example, in an educational setting:

*“..at college they would always, we'll read this out to you and you have to write it down and I can't do it, because they're doing it too fast.”* (Megan, line 123)

and in seeking work:

*“At the job centre, the job centre filled [a form] out for me because they know that I couldn't read it. My housing application, they done that for me because I told them I can't understand any of this.”* (Megan, line 131)

It could be argued that if participants had not viewed their literacy levels as a problem they would not have enrolled at the Adult Learning Centre. However, various levels of help and reasons for attendance were reported.

### **5.5.2 Reasons and triggers for seeking help with literacy**

The participants' perceived need to seek help at the Adult Learning Centre had been triggered for two main reasons: one I have categorised as employment needs; and the other personal choice. The sample was divided roughly in half along these lines.

Employment needs were associated with either current job requirements (course work associated with current employment); or future employment needs because of currently being unemployed and looking for work. The latter was sometimes reported as being associated with redundancy which had necessitated a change of career. For those seeking help because of employment requirements, the reason and trigger for attendance at the Adult Learning Centre were sometimes one and the same thing. Literacy learning was initiated through either self-referral or referral through employment support projects. This again highlighted the position of participants in not viewing their literacy as a problem per se. For many, their functional literacy had been sufficient for their employment until the requirements changed for the reasons mentioned, when they were unable to meet the new demands on their literacy skills. For example, Marion described her situation in this way:

*“I’d just been working in factories and that, so it’s not really affected me that way, but it’s not until now that I find, because I’ve got to go for a career change and I’ve got to go on computers and I’ve also got to maybe write a lot and that..... well, if I was still working in factory type jobs, I wouldn’t have bothered.”* (Line 218)

Around half of the participants reported making a choice to learn because of a perceived personal need. For example, Yvonne wanted to be able to read to her young child and help with homework when that time came; Olive initially took up learning to “fill a gap” after a close family bereavement; she struggled after her initial enrolment on a college course and abandoned it to attend the Adult Learning Centre to improve her literacy.

Among those who reported taking up literacy learning for reasons of personal choice, some had contemplated this for some time and the decision to actually enrol at the Adult Learning Centre was triggered by external events. Promotion of literacy learning, either nationally or locally was commonly cited as such a trigger. National promotion was usually in the form of television advertising of the Big Plus, a Scottish campaign which promotes the free help with literacy that is available across the country. Others began attending the Adult Learning

Centre through the encouragement of a partner or through the recommendation of friends who were themselves attending. Some participants had been inspired or encouraged to seek help by literacy tutors from the Adult Learning Centre promoting their service locally by visiting or working with community groups.

Sometimes a combination of events led to the engagement with literacy learning. Margaret described how national advertising had triggered a discussion with her husband who had encouraged her to enrol at the Adult Learning Centre.

*“...Big something [Big Plus] and I says to [husband] and he says ‘Well they keep saying they’ll teach you to read and write, why not, you know, take a deep breath, phone up and ask.’” (Line 326)*

In describing their literacy levels and reasons for accessing help, factors that participants associated with their low literacy were often mentioned.

### **5.5.3 Perceived causal factors in low levels of literacy**

As mentioned earlier, the 25 participants who were interviewed individually had varying types and degrees of reading, writing and numeracy ability and in describing these during their interviews, most participants offered reasons that they perceived as having led to their low literacy. All of these perceived reasons were reported without prompting. No questions about reasons for low literacy were asked during the individual or focus group interviews.

Six of the 25 participants reported that they had been formally tested and diagnosed as having dyslexia, three in primary school, one in secondary school, one at college and another in adulthood. A further 4 participants mentioned dyslexia in their description of their literacy learning needs. Dorothy reported that she thought she had *“a touch of dyslexia”* Margaret that she had been advised by the tutor at the Adult Learning Centre that she was *“probably dyslexic”*, although this had not been formally assessed. Margaret appeared to have embraced this diagnosis in coping with and explaining her literacy difficulties.

Stevie reported experiencing memory and communication problems, often associated with dyslexia, as well as reading and writing problems. He described himself as dyslexic throughout the interview although he said he had never been formally assessed. Debbie reported that she was thought by her employer to be dyslexic because of the nature of mistakes in her work but this had happened quite recently and she had not been formally tested.

Stevie also reported that changing schools frequently and often being kept off school by his parents to help out at home had had an impact on his literacy. Others reported missed or disrupted education, which they perceived as causal factors in their low literacy:

*“I didn't have much schooling due to ill health and family stuff and that”* (Cathy, line 8)

Several participants described their truanting from school and this was perceived by some, such as Yvonne, as both a cause and a consequence of low literacy:

*“I was useless at school, kept on skiving off and everything”* (Yvonne, line 52)

The causal factors in participants' low literacy thus discussed were, in turn, often associated with experiences which had had an impact on their perception of themselves and on how they managed information about their low literacy through their childhood and adult years.

#### **5.5.4 The struggle of being different**

In participants' accounts of their life histories, chronologically, the potential impact of their low literacy on their mental wellbeing first became apparent in their descriptions of their experiences in formal education. The majority of participants offered information from their schooldays without prompting, most frequently in their answers to my opening invitation to describe how they came to the Adult Learning Centre and what help they were accessing there. Most of the participants, at this point, described their literacy skills in terms of what they had failed to achieve at school. Participants went on to talk more broadly about their

school experiences as illustrative of how their low literacy skills came about but recounting situations and feelings which suggested that their differentness was felt by themselves and identified by others at this early stage in their lives.

Many of the participants used the words 'struggle' or 'struggling' to describe their time at school. The term 'struggle' was used with reference to three different but related aspects of school life: one described their difficulties and slowness in progressing with school work; another their relationships with teachers and peers; and a third their struggle with themselves.

#### **5.5.4.1 Struggling with school work**

Most of the participants reported having had a problem keeping up with school work or certain aspects of it and poor educational outcomes were reported in the form of exam failure, leaving school with no qualifications and, for some who moved on to further education, dropping out of college.

Some participants reported that they realised throughout school that they were struggling or making slow progress but this had not been picked up by teachers. Yvonne, who was in her 30s, believed that this was related to the lack of awareness and support for people with literacy difficulties in the era when she had been at school:

*"I found it hard when I was going through school as well, but when I was at school, they didn't have what they've got at school now. They can actually detect if somebody's struggling. When I was at school, they didn't have that sort of thing at school, that if you were struggling..... but school didn't pick up on it so it was harder for us". (Line 162)*

Megan, who was in her teens and at school more recently, however, also found that her struggle with literacy had not been detected, and she, like Yvonne, appeared to believe that it was up to the school to identify it and bring it up:



*"The whole way through school, nobody says anything"* (Line 26)

In contrast, Carol reported that she, herself, had not raised it as an issue and did not indicate an expectation that her teachers would identify a problem. Carol also had other reasons for keeping quiet.

*"I always had problems from when I was wee. I noticed that I was finding it hard, but I never told anyone, because my mum used to be bad to me, so I just tried not to say too much."* (Line 28)

Margaret, during her interview, reflected on her own awareness that she had had difficulties with reading but also her inability to understand why she performed so erratically:

*"And I couldn't understand why I could read in some circumstances, you know, I could, say, read something that's got 5 or 6 long words and know the meaning and then come back to read cat, mat and sat and forget it, I don't know how to do it."* (Line 359)

Some reported having been identified as having some difficulties, but this did not necessarily lead to action by the school. Such was the reported experience of Gordon, who also commented that his progress did not improve throughout school:

*"I went to [school] and I don't know why but my mother and father went to see the headmaster and teacher and that and [school] said 'It's just a case of he'll grow out of it.'"* (Line 427)

Some participants, such as Debbie, reflected that they had thought they were slow or had poor skills such as spelling, but did not see this as a particular issue:

*"I always struggled a bit but with certain things but I never thought that it was anything. I just took longer and got help and I usually managed."* (Line 15)

For Stevie, although it had been more recently suggested that he may have dyslexia, he perceived his struggle with school work as being associated with his frequent changing of schools and his non-attendance at other times. He described this as having impacted on his progress:

*"I never caught up with my work .... I wasn't a good reader, I couldn't write - I could write but I wasn't a good writer."* (Line 16)

Harry's struggle with schoolwork led to low aspiration and the anticipated poor outcome:

*"I knew when I was at school, I didnae hae a hope in hell o' getting' anything and I didnae get anything."* (Line 8)

Harry, later in his interview, further emphasised his lack of achievement at school:

*"You just seem to fail at everything you do, you know?"* (Line 296)

and his perception of being a failure persisted in spite of a City and Guilds qualification he had achieved after school, maintaining *"I bluffed my way through it."* (Line 385)

For some, their struggle reportedly resulted in disengagement from school or school work to varying degrees:

*"I had the same jotter in first year as I did when I left school. I just wrote my name on it and that was it. I got put down as a disobedient child."* (Katy, line 328)

Disengagement from the education system as a whole was frequently reported. This happened in three ways: prolonged or frequent absence; truanting; and formal exclusion from school. Several participants said they had missed a good deal of school because of ill health or family circumstances and this was offered by them as a reason for their low literacy. Some reported engagement in truanting, often as a result of academic difficulties, which were subsequently exacerbated by the truanting, leading to a circular relationship between the two:

*“I never used to go to school that much and I think that because even then, when I was at school, I found it hard, found the writing, it didn’t come easy. As you got older, it was harder to keep up with the work you were getting at school. It just was easier just not to go and do the work, so that’s when I think I just thought. It gets worse as you get older because you don’t realise how far behind you’ve fell.”* (Louise, line 348)

Megan reported frequent exclusions from school, which she related directly to her dyslexia:

*“... if I was to stand up and read to somebody, I can’t do that and at school, I used to always get excluded for not doing it because I’d refuse ..... I’d start stuttering, I can’t get the words out when I stand up and everybody used to laugh at us, so I’d walk out of my class and got excluded from school the whole time.”* (Megan, line 345)

As well as struggling with school work, participants reported difficulties with relationships at school.

#### **5.5.4.2 Struggling with relationships with peers and teachers**

Participants described difficulties in relationships during their school years, reporting separation and alienation from their peer group; and lack of support from and negative labelling by teachers.

Megan described her struggle with reading as something that made her different from her peers, who also recognised her ‘differentness:’

*“Everybody would be like, ‘Can’t you just stand up and read your book?’, because I can’t, everything just starts jumping in my face and I really can’t read it. Everybody else is like, ‘Oh, we can all do it,’ but I can’t and don’t know why because nobody’s able to tell us why...”* (Line 348)

Harry's account of beginning secondary school suggests feelings of alienation from the start, and his perception of being different from his 'academic' peers emphasises the role of his low literacy in this feeling of separateness:

*"Secondary school, I just felt totally adrift at secondary school. It was a totally different world where I kent I didnae fit. And I kent I was gonnae ha'e problems fae the minute I walked in and then all these people I'd never met before, all the academic ones, like I was saying before, they just soldier on and you just fall back, fall back, fall back."* (Line 356)

The concept of 'not fitting' was common in participant stories of their schooldays and some reported having no friends and always being alone. 'Not fitting' also applied to some of those who found that their literacy difficulties resulted in being labelled as different through removal from mainstream education and placement in a special school. Marion related how her enrolment at a special school was later recognised as inappropriate when she appeared not to fit into the special school either:

*"Well, when I was at school, I was not that good, so they sent me to a special school, but then again, when I got a wee bit older, special school thought what was I doing there?"* (Line 209)

Others had their 'differentness' proclaimed through being *"kept back"* and having to repeat a school year when they had made unsatisfactory progress. Labelling and separation from peers also came about through the provision of learning support, which was provided for several participants, often but not always, after a diagnosis of dyslexia. This was viewed by some recipients as a positive and helpful response to their needs but, for others the support was reported to be unhelpful or not appropriate.

Fraser's account of his experience of learning support suggested that his expectation of progress was not realised so that his separation from his peers continued in terms of what

he was able to achieve academically. His view that he did not receive an adequate amount of support was strengthened by his experience of adult learning:

*“Yes I got basically one-to-one support at primary school which I found sort of, obviously coming here and then basing it on that, I didn’t find very good but was obviously better than nothing, and I got support in secondary school as well but that was again a hold back..... I didn’t feel I got as much support as I needed to sort of make progress in my exams and that that I think I should have.....”* (Line 29)

Separation from peers at school was associated with bullying according to many participant accounts. Harry described his ‘struggle’ at school as:

*“Just one constant round of bullyin’ and hassle.”* (Line 139)

Some participants reported what appeared to be a sense of their own responsibility in the bullying they experienced. Gordon described himself as being “a soft touch” at school for people to “take the mickey” out of him. Sandie described her immaturity and poor socialising skills related to her poor performance at school, believing this to have led to the bullying she experienced:

*“.... I have realised that now and I hate even talking about it, it upsets me so much because there was no support there and nobody realised I was being bullied for being myself but I didn’t realise I was doing anything wrong and there was no support there to help me get over that bullying, it was all my fault.....”* (Line 234)

Margaret declared that the bullying she suffered from her peers was something she perceived to have been encouraged by being humiliated by one of her teachers:

*“... my teacher thought making me read out to the school was one of the best things there was. It wasn’t. It was not. It was so... ..the children they were the worst cos it was like another notch on... Oh (sighs).. ‘Well, she’s thick, stupid, now she can’t talk.’”* (Line 637)

Such perceived unfair treatment by teachers was echoed by others. Some teachers were reported as perpetrators of bullying in spite of their awareness of the child's difficulties with literacy. Like Margaret, several other participants reported having to stand up and perform in front of the class. For example, Karen, who was assessed and diagnosed as having dyslexia when she was in Primary 3 reported:

*"I was actually bullied by one of my school teachers but that got sorted out. Yeah, cos he used to make me stand up and do times tables I couldn't do... and made me read in class and I couldn't do that."* (Line 277)

Some people reported having felt humiliated through asking a teacher for help so that they subsequently kept quiet to avoid further humiliation:

*".. I was never taught to do, oh, what do they call it? I call it joined up writing, because that's what happened to me. I'd actually left one primary school during the summer and I was starting a new primary school and I remember going out [to the teacher's desk], I can't remember what we had to do, but I'd just gone out and said, 'Excuse me, Miss, I wasn't doing.....,' and she says, 'Get back to your chair and try' and she never came back to ask me how I was getting on and I never asked. Whether I'm looking for a blame but I could remember that. So I've never, ever asked, that was it. I just had to get on with it."* (Olive, line 398)

While Olive's need for help had not been acknowledged by her teacher, some participants reported having been negatively labelled at school when their literacy difficulties had not been recognised:

*"They used to think that I was disruptive or that I wasn't listening all the time but I didn't have the sort of resources to help me with my dyslexia so.."* (Ralph, line 31)

Other negative labels were reported e.g. Dorothy was considered by her teachers to be backward and Katy, as mentioned above, disobedient. This contributed, along with the other

reported negative school experiences, to participants struggling with feelings about themselves.

#### **5.5.4.3 Struggling with self**

Participants frequently reported that their literacy problems had affected their confidence at school and had led to low self-esteem and self-doubt. Parents were sometimes reported as being unsupportive and there was evidence of stigma coaching whereby awareness of stigma had been raised by parents and family members. This effect had reportedly continued into adulthood.

Harry declared that *"the confidence gets kicked out of you at school"*. He further suggested that his earlier experiences in school, including labelling and separation from his peers, now prevented him from asking questions in adulthood:

*"You kinda think 'I'm no asking questions' cos at school when you ask ... kids that ask questions and dinnae ken what they're askin' they get humiliated and humiliated and it goes on and on and on and then it suddenly becomes part of your make up and that's why you see the rest of the class dividing. And those that can, get on and those that can't just go further and further back."* (Line 686)

Parents were also reported as a source of low confidence and poor self-esteem. Ralph described the effect of his parents' judgement on his self-perception:

*"Cos my mum used to say to me 'You're so stupid' sometimes you know and that used to really ... you know, before when you were younger you [think] 'But I must be stupid then if my parents or even someone outside tells me I'm stupid.'" (Line 390)*

Parents were reflected on by some others as having been unsupportive or unsympathetic when participants had had a diagnosis of dyslexia. Reported parental responses included denial of their child's dyslexia, thus threatening the child's identity, and being impatient with their child when they were slow with literacy activities. There was also evidence of stigma

coaching by parents and others. For example, Margaret stated that her avoidance of revealing her literacy problems in adulthood was influenced by her mother's response to Margaret's news that she may have dyslexia:

*"..... and she says 'Well don't bother because it can be a detriment against you' so I've always had that stuck in my mind. It's a detriment, you don't..... you know what I mean."* (Line 486)

Through these accounts of school experiences, this period of participants' lives appeared to be one where their low literacy often highlighted them as different and led to stigmatisation, bullying and humiliation.

#### **5.5.4.4 Schooldays - "probably the toughest time in my life"**

It would appear that even being assessed as having dyslexia did not necessarily protect children from struggling with schoolwork and with teacher-pupil and peer relationships. Fraser, whose dyslexia was diagnosed early in primary school, described school as:

*"very tough and I would say quite mentally abusive from the point of view it was, I always felt that I was basically up against the wall..... I would say it's probably the toughest time in my life, certainly I've never experienced anything like it and hopefully won't again."* (Line 73)

The majority of participants thus reported their 'differentness' from their peers in coping with schoolwork and their feelings and experiences of stigmatisation because of it. Their relationships and feelings about themselves were affected by the stigma of their low literacy, and both felt and enacted separation from their peers and their school were described, suggesting that their childhood had been spoiled by their poor educational experiences and by the stigma and associated mental wellbeing effects of their low literacy.



### **5.5.5 Legacies of a spoiled childhood**

Awareness of stigma potential and associated unwillingness to disclose low literacy in adulthood appeared to be associated with lack of parental support and stigma coaching. Poor educational experiences and outcomes due to: their literacy difficulties being either unrecognised or inadequately addressed in childhood; their limited abilities in coping with day to day literacy requirements; and the felt and enacted stigma experienced by most of the participants at a young age would appear to have influenced their expectations and experiences in the workplace and in adulthood in general. This too had had a negative impact on their social and mental wellbeing.

#### **5.5.5.1 Living with low literacy - “it wears you down”**

Low literacy in itself may have negative implications for social and mental wellbeing and from the participant accounts it appeared that the felt and enacted stigma associated with low literacy also had an impact on their social and mental wellbeing.

Bert described living day to day being unable to read as “*a strain, mentally.*” Moira reported that her struggle with written assessment tests had been a constant stress over a long period because of work requirements. She attributed her inability to fulfil the demands of her job to lack of confidence with literacy activities, leading eventually to her losing her job and being treated for depression as a result. Yvonne who, unlike most of the other participants, claimed that she did not hide her reading problems in any situation, nevertheless found it stressful when she was unable to perform certain tasks at work and had to be taken off these duties. She reported wanting to try them but was slow and became stressed when she couldn’t understand things.

Harry declared that “*it wears you down*” and that he felt “*weak and depressed*” because of his problems. He reported having had treatment for stress because he “*didn’t know how to handle things.*” Stress and other diagnosed mental health problems were fairly frequently

reported. These included nervous breakdown, depression, eating disorder and panic attacks. Some mental health problems, as in Harry's case, were directly attributed by participants to their low literacy. For other participants, mental health problems were sometimes associated with other identified life circumstances but were reportedly exacerbated by their low literacy.

For most participants, once they had settled into attending the Adult Learning Centre, they reported feeling relaxed and enjoying the classes. Some, however, continued to experience stress associated with performing literacy activities. Stevie described panicking in such situations, including when he was carrying out exercises at the Adult Learning Centre.

The stress of living with low literacy was, however, most often related to passing and covering or otherwise avoiding disclosure. Several participants spoke of the stress of living with low literacy in terms of the need to constantly cover up and worry about situations arising where literacy skills might be required. This was confirmed in the focus group discussions and summed up by Jason who described it as:

*".. having to be one step ahead in case you're handed a form or something."* (Focus group 1)

For some participants, the stress was reportedly caused by the fear of stigmatisation associated with their low literacy:

*"I never told anybody, it was always just something that was hidden away back so nobody could see it. I don't know why. I think that's just no confidence not wanting to tell anybody in case they think I'm an alien"* (Megan, line 521)

On a positive note, informal support was available to most, but not all, of the participants, who reported having either a family member or a friend to help them with literacy activities on a regular basis. This included help with reading official correspondence, such as solicitors' letters or hospital appointment letters, and completing forms such as applications for housing or welfare benefits. There were, nevertheless, widely varying degrees of

dependence on others. Some participants described eliciting help with some specific literacy activities:

*“I have a little bit of help. My dad’s pretty cool he’ll like read some letters for me and stuff like that, if I remember to give it to him..... Yeah I’ve got pretty much a good support mechanism”* (Ralph, line 55)

Others reported that they were very dependent on others in relation to performing literacy activities in general. This was most apparent from the accounts of younger participants. Many of those who were in their teens or early 20s lived with one or more parents and there appeared to be a heavy reliance on these parents. Rather than receiving only assistance to perform necessary literacy activities, these young people more commonly stated that their parents filled out forms for them; read information leaflets to them; provided any over-the-counter medications they required and accompanied them to the doctor:

*“I have to get my mum to write the forms for [repeat] prescriptions or that .... my mum deals with all my paperwork, my benefits and all that, my mum deals with all that..... “*  
(Pauline, line 199)

Although Pauline was planning to get her own house she declared:

*“Yeah well, I probably won’t take over my own benefits and that.”* (Line 204)

Katy expressed appreciation for having what she described as a *“big strong family”* who provided lots of support, pointing out that many people don’t have that. Indeed, lack of support from partners or others within their family was described by several people. Megan said that she had lived with a partner who frequently called her stupid, while denying his own difficulty with reading. Others gave reasons why they didn’t have support at home. Dorothy stated that her partner was unable to help due to his mental health problems, while Harry described his wife as *“too busy”* with her job to help him. These descriptions of participants’ personal circumstances served as a reminder that those who share a home with people with

low literacy may have a number of reasons why they do not provide literacy support and it may also be wrong to assume that those who do provide informal support have adequate literacy. There are also disadvantages in over reliance on others as demonstrated in a healthcare context in the next chapter.

As well as the proposed direct effects of living with low literacy, other effects which were sometimes associated with the literacy itself and/or the stigma associated were reported, such as low confidence.

#### **5.5.5.2 Living with low confidence**

Many participants reported that the reduced confidence they suffered in school either remained with them or resurfaced in certain situations in adulthood:

*"..... there still is times where my confidence will go down to an ultimate low which just reminds me of the days when I was at school and obviously try and keep myself from getting into that situation but obviously it is one of these things. I think that's something that I have got to try and get over. (Fraser, line 126)*

Even when people were generally confident, they found that certain situations or topics of conversation presented a stumbling block for them:

*"I've always been good with confidence itself with things like speaking to people about certain subjects but if it's an educational matter I can't, you know, you've no confidence to talk about what you don't know, yeah so, rather than ..... just try and change the conversation." (Jack, line 59)*

Low confidence was associated with literacy problems in other ways. As mentioned previously, Moira offered her lack of confidence as a reason for her inability to use the computer for a test. She appeared to believe that her literacy skills were adequate, although she demonstrated a poor understanding of an assessment at work.

Carol's low confidence which she attributed to her inability to read was reported to affect many of her day to day activities:

*"I don't feel any confidence about myself. .... I've got no confidence just to go out. I can't just go in to like, if I was going into town, just me and [daughter] to get [daughter] her tea, I couldn't just go into McDonalds or anywhere to get [daughter] her tea, I can't do that. I've got to have someone there with us. Or like even buying her something, there's always got to be somebody there with us."* (Line 453)

In contrast, Margaret declared that being outgoing and appearing to be confident was a way of concealing her low literacy:

*"I would have never got a job, so I always looked for jobs where I talked myself into the job. I'm very, very outgoing but I think that's because I have to be."* (Line 92)

For many participants, low literacy was clearly associated with other feelings and experiences likely to impact on confidence and mental wellbeing in general. For example, being considered to be thick or stupid or feeling that they were stupid either in general or in particular situations, were commonly reported features of participants' life stories as was fear in various social situations.

#### **5.5.5.3 Living in fear**

Words such as *"fear," "scared"* and *"frightened"* appeared frequently throughout the participant accounts, in relation to their anticipation of other people's reaction if they revealed their low literacy to them; their anticipation of stigmatisation; and in their descriptions of going along to the Adult Learning Centre for the first time.

Louise described her fear of what people might say about her if they found out she had difficulty reading and writing:

*“... maybe it's just scared, maybe it is what their reaction will be, you know, going away and saying 'Oh, she can't spell right' or something like that.....Not they'll react to you but maybe what they'll go and say to other people.” (Line 234)*

Fear of stigmatisation featured in many participants' reported feelings about revealing their low literacy. Some participants anticipated that people such as healthcare staff would judge them to be stupid, whether they declared their low literacy or not. Harry said that he believed this of a healthcare consultant whose clinic he was attending but to whom he had not mentioned his low literacy. He further perceived this to be the reason for the lack of explanation about a medical problem and described what he imagined the consultant's thought pattern to be:

*“You look the type, you're just stupid, so dinnae tell him, you dinnae ha'e to tell him, he doesnae ken any better.” (Line 288)*

This concept of 'looking the type' suggests stigma in the literal sense of the word, that is, as a visible sign. The concept of visible stigma also appeared in Barbara's response to my question about being offered help with forms at a healthcare consultation:

*“I would think, 'Oh my God, she knows. I've done something. Some thing, some sign that I've done, have I got something on me? I've done something.' I would feel embarrassed..... 'Why is she asking me that? Is there something on me?'” (Line 586)*

Harry's account depicted feelings of being discredited i.e. he believed his differentness was immediately perceivable by the hospital consultant. This was in spite of the fact that Harry was articulate and well presented, as was Barbara. Her comments suggested a perception that she could successfully pass as normal, believing that her 'stigma' was not perceivable by others but she did admit to a fear of becoming discredited, and expressed awareness of her stigma potential.

The prospect of being laughed at was also frequently reported as a reason for participants keeping quiet about their low literacy. For many, this fear was linked to previous experiences. Gordon restricted who he told about his low literacy to avoid people *“taking the mick,”* and Carol described limiting the number of friends she had told about her low literacy for a similar reason:

*“I try not to tell a lot of people because then when I argue with them, like my wee sister and that, she brings it up and stuff. So it makes me feel low. So that’s how I try not to tell anyone. Some of them know.”* (Line 79)

The anticipation of experiencing negative reactions from others was also reported as significant. Nervousness and anxiety featured frequently in situations where literacy activities had to be carried out in public. Several people stated that worry affected their ability to participate in meetings or courses connected with their job because their thoughts were focused on their anticipation that they may have to read or write something. Barbara described her anxiety at having to complete a form in public as being so bad that she was unable to spell her own name.

Participants used the term ‘panic’ and described feelings of panic in situations where literacy skills may be required or where there was the potential for their low literacy to be revealed.

Harry described the panic he felt when he was given a task he was unable to do at work:

*“I had to go back and say ‘I dinnae ken how to dae this’ and all the panic buttons getting pressed. ‘What will I dae? what will I dae?’ And then circumstances would come along and then grab it and then [a senior person at work would say] ‘You’re takin’ too long, do you ken what your daein? You dinnae ken how to dae that! Here come along and dae that, come along and dae this’ and all that, ken.”* (Line 472)

Having to disclose to his superiors that he was unable to carry out the task and the subsequent consequences of being taken off a particular job and given something more basic to do, was an experience Harry described as having happened to him many times.

Several participants reflected on how frightening it had been to come to the Adult Learning Centre for the first time. Bert acknowledged that there would be other learners in the class but found it frightening to join them because he believed that they would all be at a higher level than he was. Many indicated fear related to having to admit to someone that they had difficulties, or that they would be considered stupid, a fear reported by Barbara, who didn't keep her first appointment due to *"pure nerves."*

*"It was a very, very upsetting... I found it very hard to explain to somebody. You're very very frightened that they think you're stupid and that you're no use but I'm not am I? How do you say, you're not going up to somebody to say, look, I can't do that and then having them look and say, 'Are you daft? Are you stupid?'"* (Line 34)

Olive recounted that it had *"taken courage"* to go along and enrol at the Adult Learning Centre and described having to *"sit there and admit my English wasn't good and I missed a lot of school and my maths"* when she first met with the tutor at the Centre.

These accounts of participants' original help seeking at the Adult Learning Centre suggested that they did not perceive that they would be entering an environment where there were others with similar stigma potential or that the tutors would be accepting rather than rejecting and stigmatising.

Fear of exposure, among other things, often led to voluntary separation from others. A few participants spoke about 'stepping back' in social situations because of the fear of being asked to do something involving literacy skills. Bert's description suggests his feeling of separateness as well as his own actions to physically separate himself from potential exposure:



*“.... you sort of step back like in a crowd, you sort of feel a wee bit of an outsider all the time, you know, no matter where you are.... I think I’m doing what most people do that can’t read you step back from the crowd. Especially in a group or something because the worst thing that could ever happen is ‘Oh, Bert, could you just read that line for me?’ Boof, your whole world just sinks, you know what I mean?. There’s nothing worse and that’s why people always step back near the door just in case that happens.” (Line 458)*

The concept of ‘stepping back’ appeared in other terms such as ‘falling back’ or ‘going further back’ in the context of participants removing themselves from situations when low literacy made it difficult to engage. The social isolation resulting from these acts of separation appeared to have been preferable to being identified and separated because of low literacy. Social exclusion by others was also reported.

#### **5.5.5.4 Social exclusion**

Some participants commented during the course of their interview that *“most people can read and write,”* thus suggesting that their own lack of skills did not fit with what they perceived to be social norms.

Feelings of being socially excluded or isolated in adulthood by others because of their low literacy were expressed by several participants:

*“... you feel looked down on, all that kind of stuff. To me, it wouldn’t have mattered how pretty you looked, how well or unwell dressed you were, that’s a stigma I suppose, that, ‘Gosh, look at her. She can’t spell this or write this...’” (Olive, line 514)*

Exclusion from full engagement in some social interactions was an issue for several people who described particular difficulties and behaviours, such as being unable to get their point across or pretending to take things in. These included exclusion from participation in some work and extracurricular activities. Some participants reported a reluctance to disclose their

low literacy to others because of the prospect of being described as a “freak” or other similar terms suggesting stigmatisation and exclusion.

Several participants expressly stated feeling isolated and some declared that they had no friends. Harry described almost complete social isolation which he related directly to his low literacy and perceived as placing him in a separate class from others he may encounter socially:

*“I dinnae have any friends. I probably have, socially, nae friends whatsoever. The only friends I have are people I work wi’ and that’s only because I work with them. Cos it’s just the same cycle, once... ‘He’s an idiot’ they don’t want anything to dae wi’ you. I just dinnae seem to get past that social barrier, ken you dinnae get oot o’ your ain class, ken?”* (Line 738)

Harry’s sense of the effect of his low literacy appeared overwhelming throughout his account; he did not seem to recognise any positive attributes in himself and seemed to believe that, in any social interaction, his stigma became immediately obvious and he was thus discredited. Harry avoided social situations or social interaction as far as possible because of what he perceived as inevitable stigmatisation. His sense of inferiority was further illustrated when he was describing an encounter with his general practitioner (GP), whom he felt treated him in a much better way than the doctors at the hospital:

*“Harry, how are you doin? Come and sit doon. Let’s just see that’ and then explains it to you. ‘Oh right’ and dinnae dae this dinnae dae that whatever it is. And then great! ‘Hey I feel .. I’m important’ ... well, no important, but you feel good about yourself ‘Aye, right, somebody cared.’”* (Line 541)

While Harry clearly reported feeling positive about being treated in this way, he very quickly and emphatically corrected himself when he had declared that it made him feel important.

Stigma and social isolation were often felt rather than enacted.

#### **5.5.5.5 “They can’t even read and write”**

Sometimes stigmatising comments were reported as having been made by others in a general or non-personal way in a social group or gathering. Derogatory comments about stupidity or about people with literacy problems were nevertheless described as being personally felt by participants who were in these social situations:

*“... and they were saying ... ‘Oh, there was people at [a named group] and they can’t even read and write’ and I’m just sitting there going oooh! Things like that. I wouldn’t like my own friends to know” (Louise, line 332)*

Ralph described his sensitivity to being called stupid, even in jest, because of his previously mentioned experience of having his mother call him stupid:

*“I find it sensitive you know when some people would speak about something I find it personally sensitive. I’ll give you an example like, you know some people will talk, will say like, you know, talk normally and they’re not meaning it in that way but I take it in that way, personal. They might be talking about something in general and I feel it’s like they might say to me ‘Oh you’re so bloody stupid!’ but I would feel that that was, but it might have just been used in a context, if you know what I mean and stuff like that but I’ll take it personally if it’s addressed at me, if you know what I mean.” (Line 380)*

Childhood experiences were thus reported to have had effects which continued into adulthood. As adults, nevertheless, participants described having a greater degree of control over revealing their low literacy to others and subsequently experiencing the associated effects.

### **5.5.6 Adults taking control**

The descriptions of experiences at school depicted many situations where low literacy or slow progress was exposed to peers within the classroom. In general, the school environment does not allow for hiding or covering up slow progress and children and young people tend to know where they and others sit in the scale of academic success. Participants, in their descriptions of adult situations, depicted a greater degree of control of information about their low literacy although felt and enacted stigma and at times, exposure when faced with the completion of literacy activities in the presence of others, featured in their accounts. In situations where participants wished to avoid exposure, they would not disclose their low literacy and could employ passing or covering behaviours. In other situations they would reportedly select when and to whom they would reveal their difficulties. Disclosure itself appeared to be complex and for individual participants, stated attitudes and behaviours towards disclosure of low literacy did not always match, as discussed in the next chapter. These behaviours and actions nevertheless, brought their own stresses.

#### **5.5.6.1 Passing and covering**

Passing i.e. making a particular effort to display what is considered to be normal behaviour in a particular social group was reported by participants. Bert reported passing behaviour when he was at work:

*“I sit with a paper same as everybody else but I am only looking at the pictures, I am not reading it, I am trying to read it you know but not really showing that I am trying to read it.” (Line 100)*

In this way, Bert used the newspaper as a disidentifier, a tool implemented to detract from his low literacy.

Barbara reported feeling well received in social situations, and she appeared to believe that her public presentation of herself allowed her to pass as normal which helped to maintain the

concealment of low literacy. She reported that her writing and spelling abilities did not match her other attributes thus describing her possession of a stigma, or undesired 'differentness' from what might be anticipated.

Covering, or downplaying a stigmatising condition, such as displacing the stigma to a lesser condition, was also reported by participants. Making excuses about bad handwriting was a commonly reported covering behaviour. For example, Olive described what she would say in a situation where she was asked to scribe for a discussion group:

*"My writing's terrible and none of you would make it out' and just go 'I'm not doing it'"*

(Line 348)

Thus, the accounts of Olive and others who used this excuse, suggested that bad handwriting was a less stigmatising condition than low literacy. Other covering behaviour was demonstrated. Some participants were keen that people should know about their dyslexia, suggesting that they were trying to avoid the stigma of 'other reasons,' which would appear to be less desirable to have attached to them. For example, Stevie reported that he told people about his dyslexia because he felt embarrassed that people might think he didn't want to read and write. Fraser explained that he felt he should let people know about his dyslexia or they might think that there was no reason for his low literacy:

*"I've been quite open with that [his dyslexia] from basically the minute I started working, I always obviously bring it up in interviews and things like that but if there's any measuring [work task], most of the people do know and you know I am not ashamed to admit it because I think you have to basically say otherwise people will just say well there's no reason for this, but at least if people know you can be open with them"* (Line 215)

Ralph described a situation whereby his reason for revealing his literacy was to obtain a clearer explanation, but in receiving a simplified explanation he described covering by pretending to understand:

*‘I kind of say ‘Can you explain that to me,’ they’ll say ‘Yeah blah de blah blah’ and I’ll say ‘OK thank you’ and I kind of mask it as if I understand if I don’t.’ (Line 421)*

Ralph went on to explain that he would do this if he felt uncomfortable, suggesting that once a simpler explanation had been given, his anticipation was that further requests for help would lead to stigmatisation or a negative response, hence the covering, in spite of having revealed his dyslexia.

Other examples of covering were described. Some also described making excuses, such as saying that they had left their reading glasses at home if required to read something, an excuse which is commonly reported as an example of a coping strategy, which may also be considered to be a form of covering by attributing their inability to read something to poor eyesight.

#### **5.5.6.2 Information control through selective disclosure**

Participant accounts suggested that, in adulthood, they had had more control over who was allowed to know about their low literacy. Some stated that they were open about their problems while others did not want anyone to know. Most of the participants in the latter group reported that very few people around them were aware of their low literacy. Indeed, several participants reported that friends and even close family members had not been informed, for example, Bert declared that he had not revealed his low literacy to his wife of many years.

Many participants were neither completely open nor completely private about their low literacy. Rather they disclosed to selected people, often making the decision whether to disclose or not at the time of an encounter with the person in question. Such a decision was reportedly based on factors such as the perceived benefit of disclosure or the anticipated response of the other person. While disclosure was sometimes forced by a particular situation, such as having to complete a form on the spot, participants’ descriptions

suggested that, for much of the time, they were in a position to decide whether to disclose or not.

While this may have been an advantage in terms of people's social and mental wellbeing in avoiding stigmatisation, as already mentioned, the associated passing and covering can be stressful and the reasons for such information control were, for the majority of participants, associated with previous experience of stigmatisation. There are also potential disadvantages in this type of information control, particularly in healthcare situations, as demonstrated in the next chapter.

#### **5.5.6.3 Literacy learning and improved mental wellbeing**

For many participants, as already reported above, initially engaging with the Adult Learning Centre was not easy. Several people reported having made more than one attempt to go along for the initial enrolment meeting and their descriptions demonstrated that it was necessary for them to take control of their feelings of anxiety, and their fear of exposure and stigmatisation, in order to embark on their learning. This applied to those who were taking up literacy learning through personal choice as well as those who engaged with the Adult Learning Centre for reasons associated with employment.

The Adult Learning Centre was highly regarded by all participants. In spite of their fears and anxiety about seeking help, the majority of participants spoke of their first contact and interview with the Adult Learning Centre and described these as positive experiences. They expressed positive feelings about their continued attendance at the Adult Learning Centre and emphasised the acceptance and the absence of stigmatisation by their literacy tutors and their learning peers:

*"I'm finding that if I'm in an environment like this, with other people around me, it's a less of a stigma, if you know what I mean, and stuff like that."* (Ralph, line 489)

The majority of participants also made some comment on the positive effect of learning and improving their literacy skills, mainly in relation to increased confidence but also on other aspects which suggested improvement in their mental wellbeing.

Asking more questions in encounters such as healthcare consultations, meetings with solicitors or appointments with other agencies, was an outcome reported by several participants. Margaret, as others, identified this change in her behaviour in healthcare situations as being directly related to having the confidence:

*"I have an idea of what I'm talking about. I had an idea before but I didn't know how to say it. Now I say it, now I say what I think I have to say. And if I've got it wrong well I'll just say 'If I'm saying it wrong, please explain why.. how I'm saying it wrong' That, I have got confidence, yeah. I'm the one that wants to know how, why, when and who now."* (Line 112)

Thus Margaret reported that she would be more likely to ask for help if she wasn't sure about something and this was reported by others, including some focus group participants:

*"Since I started coming here [Adult Learning Centre], I've started to say 'I have some difficulties filling in this form.'.... I used to be frightened but I'm not now"* (Evelyn, Focus group 1)

It may also be the case that the newfound confidence engendered self-efficacy in terms of further learning. This was suggested by Bert's description of how attending the class had changed him:

*"When I first started the class, I didn't want to talk too loud, you know, because I didn't want anybody to hear me. Now, they tell me to be quiet. It is all about confidence, if you can get that confidence to want it and the person who is teaching you, you have that communication, if you have got that then you have made it, it's there for you to grab it."* (Line 473)



Several participants reported that others in their family had noticed the change in their confidence. Some made comments about continued feelings of confidence and perhaps being dependent on the literacy classes to maintain these feelings. Gordon said he *“would be snookered”* if he couldn’t come to class, a sentiment echoed by Barbara:

*“I certainly wouldn’t want to not come. I need the confidence, I just love it.”* (Line 50)

Dorothy described literacy learning being good for helping her to organise her hospital appointments rather than missing them, which had previously had an impact on her relationship with healthcare staff.

*“I think also the fact that you’re exercising your brain coming here but in the past if an appointment came, I know it sounds silly now but instead of filing it or writing it down in the diary I’d just put it away and just forget this. Now actually people were getting a bit like ‘What’s she playing at?’ whereas now like I know I’ve got like the block for [son], the block for myself you know.”* (Line 369)

For some, improving their literacy skills had been part of their treatment or had contributed to their recovery from mental health problems or difficulties such as bereavement.

Cathy was taking part in a creative writing course as treatment for mental health problems and was referred to the Adult Learning Centre because of her need for support with literacy. She spoke of *“getting in a state”* when she first attended class but reported feeling *“much better”* having mastered punctuation, letter writing and use of the computer. Jack had also suffered mental health problems, had lost his job and was finding it difficult to get work because of his low literacy. He described the difference that learning had made to him and to his hopes for the future:

*“... doing it here has been great, absolutely fantastic you know. The English has really brought me on and you know everything’s rosy - I’ve never been so happy as I am at this period in time, you know, just doing this. I know I’m not working just now*

*but another year's time I see myself as working, but I'll be ready, I'll be ready then you know, it's given me two years of this."* (Line 605)

For Olive, it would appear that seeking literacy learning may have improved her mental wellbeing in other ways. She reported that she had never discussed her literacy difficulties with anyone before. During the initial discussion she had with the tutor at the Adult Learning Centre, she realised that there were explanations for her low literacy of which she had felt so ashamed:

*"when I came here and I got interviewed by [tutor], before you start your class, you come and you talk to [tutor], he interviews you ..... He talked to me about school and that came to me then. It was the writing I was so ashamed about, when I spoke about that and that's when it came to me, oh, right enough, I remember there that I left there and I went there and then that day came to me, for some reason, in the class ....."* (Line 546)

Olive was recalling the incident described earlier in this chapter when she reported having been refused help from a teacher and she related this and stories of other incidents which, during the discussion with the tutor, she recognised as having affected her learning at school. Olive described this revelation as something that gave her the confidence to learn, which again, suggested improved self-efficacy.

The example given by Olive was echoed by Margaret, who appeared to retrospectively 'recast her biography' in a more positive light, through talking about and addressing her literacy difficulties. In her case, the suggestion that she may have dyslexia was reported as a turning point. Having reportedly been told so often before that she was dumb and stupid, she now stated adamantly *"I was not dumb and I was not stupid."* However, Margaret's review of how her life had been affected by her low literacy included feelings of anger that this had not been addressed earlier:

*"I'm not ashamed, no I'm not ashamed, I'm annoyed and I'm mad that I have [dyslexia] and it's not been picked up on....." (Line 404)*

Katy, whose dyslexia was diagnosed in her third year of secondary school described how it felt to realise that there was a reason for her perceived problems at school:

*"Well, you sorta like start to think because of all these years at school, you start to think 'Maybe I am stupid maybe I am just, don't want to learn' you know, and then you find out you've got this thing and you're like 'What is it?' And you've got to find out about that and find out how to deal with it and then how to come on from it, do you know what I mean? It's a lot to take in especially when you're at school and then it's just how you work on it from there, so.." (Line 339)*

Regret was mentioned by several people in describing their feelings about their history of low literacy or starting their learning later in life. Stevie expressed regret that he hadn't taken up the educational opportunities presented to him when he was young. Some older participants expressed regret that they hadn't sought help with their literacy problems sooner. Margaret stated that she would have liked to have had a career and Bert expressed a wish that he had taken up learning 20 years ago. Not everyone indicated that they held such a view. Olive acknowledged the potential for regret but declared:

*"... sometimes you can go down the road, which I don't allow myself .... 'Oh gosh, I should have or could have done ten years ago,' but I think 'Olive, no, the life you had, you were happy.' This is the time to do it, obviously, but that's the way I feel anyway, that this must have just been the right time." (Line 294)*

She reported that she had been happy child rearing and had no desire to enter the workplace.

Overall, then, engaging in adult learning was associated with improvement in mental wellbeing for most participants. Nevertheless, the effects of previous experiences were

reportedly felt and could be considered to be significant in the lives of those with low literacy who had not accessed learning.

## ***5.6 Conclusion to this chapter***

Participant accounts have suggested that for them, labelling and separation has been experienced at an early age, due to both their own feelings of being different and to the attitudes and actions of peers, teachers and sometimes parents. This would appear to have influenced participants' attitudes and feelings towards disclosure of their low literacy. They attributed their anticipation of stigmatisation to their childhood experiences. Living with low literacy and with associated stigma was reported to have affected the social and mental wellbeing of participants in adulthood and the continued fear of stigmatisation had meant that they exercised varying degrees of control over the information regarding their low literacy. The influence of this in a healthcare context is explored in the next chapter.

## Chapter 6. Exploring links between low literacy and poor health

### *6.1 Chapter overview*

This chapter examines the healthcare and self-care experiences of participants in the context of the three research questions: 'What are the perceived and experienced pathways between low literacy and poorer health?;' 'What resources and coping mechanisms do adults with low literacy employ to help them navigate the healthcare system and to carry out self-care activities?;' and, 'What kinds of changes in health service provision might improve service accessibility and healthcare and self-care experiences for people with low literacy?' Participants' reported attitudes to disclosure management in relation to their low literacy are examined and participants categorised accordingly. Few participants had explicitly revealed their low literacy to healthcare staff, supporting the notion of a 'hidden population.'

Participant accounts are analysed in relation to each of the research questions in turn. The findings indicated that people with low literacy experience difficulties which impact on their access to healthcare services; on their self-care activities; and on their social and mental wellbeing. Communication with health services and healthcare staff was frequently reported as poor. In addition to the findings presented in the previous chapter, which demonstrated participants' experiences of felt and enacted stigma, this appeared to impair relationships and potential relationships with healthcare staff in such a way that opportunities for support with healthcare and self-care activities are either not offered or not taken up. The potential for those with low literacy to improve their literacy in a healthcare context also appeared to be hampered by the feelings of or anticipation of stigmatisation.

Suggestions for potential solutions to address low literacy in relation to healthcare and self-care are presented and consideration is given to whether these are likely to be acceptable or

to engage the relevant population, taking into account the reported attitudes and behaviours of participants, particularly in relation to disclosure of low literacy.

The chapter concludes that the findings suggest that people with low literacy also suffer discrimination because of institutionalised barriers within the NHS and these, too need to be addressed.

*“We took a look  
We saw a Nook.  
On his head  
he had a hook.  
On his hook  
he had a book  
On his book  
was ‘How to Cook.’*

*We saw him sit  
and try to cook  
He took a look  
at the book on the hook.*

*But a Nook can’t read,  
so a Nook can’t cook.  
SO ...  
what good to a Nook  
is a hook cook book?”*

Dr Seuss<sup>189</sup>

## **6.2 Introduction**

The previous chapter presented evidence that low literacy has had a considerable impact on participants' mental health and social and mental wellbeing both directly from living day to day with low literacy and through the associated felt and enacted stigma. This reported impact contributes to answering the first research question (What are the perceived and experienced pathways between low literacy and poor health?) particularly in relation to poor mental health but also in relation to other potential links identified in answering the first research question. Stigmatisation and social and mental wellbeing would also appear to influence the need for and the implementation of coping strategies explored in Research Question 2 (What resources and coping mechanisms do adults with low literacy employ to help them navigate the healthcare system and to carry out self-care activities?) and this needs to be acknowledged in examining solutions in Research Question 3 (What kinds of changes in health service provision might improve service accessibility and healthcare and self-care experiences for people with low literacy?).

Common to all of these questions was the influence of participants' disclosure management strategies which appeared to impact on their communication and relationships with healthcare staff and on their likelihood of enlisting help from healthcare or associated staff.

## **6.3 Disclosure management in a healthcare context**

The participant sample was drawn from a population who had disclosed their low literacy through accessing adult learning. However, disclosing in this way did not necessarily mean that participants were open about their low literacy in other situations and it was clear from their accounts that they exercised a considerable degree of information control. In order to explore the extent of information control and conversely, the extent of knowledge healthcare staff were likely to have about patients' literacy needs I focused on participants' *reported* attitudes towards disclosure and ways of managing situations in order to reveal or to avoid



revealing their low literacy to healthcare staff. I identified from the accounts of participants three positions. Participants claimed that they either: were generally happy to reveal their low literacy to others with whom they were in contact; did not wish to reveal their low literacy to anyone; or were between these two extremes and disclosed their low literacy to some people and not to others. I assigned each of the participants to one of three categories: Revealers; Concealers and Limiters (Table 5).

**Table 5: Categorisation of participants according to reported attitudes to disclosure**

<b>Revealers</b>	<b>Concealers</b>	<b>Limiters</b>
Carrie	Barbara	Cathy
Chloe	Bert	Carol
Debbie	Harry	Gordon
Dorothy	Jack	Katy
Fraser	Louise	Olive
Moir	Megan	Pauline
Sandie		Ralph
Stevie		Karen
Yvonne		Marion
		Margaret

### **6.3.1 Revealers**

Those who claimed that they were willing to reveal their low literacy to others I categorised as Revealers. Nine of the 25 interviewees were categorised as Revealers (Table 5). However, most of the participants categorised in this group did not indicate that they had revealed their low literacy to healthcare staff.

Dorothy stated:

*“Everybody knows and everybody encourages me”* (Line 442)

Like Dorothy, other Revealers declared that *“everybody knows”* but some appeared to make assumptions about who actually did know about their low literacy or that they had shared this information when they had not necessarily been explicit about it. Several participants seemed to believe that once they had disclosed their low literacy ‘they’ [people in the health service] all knew about it. Stevie was clearly under the impression that his literacy needs were common knowledge across the health service:

*“...they've got all my records and I asked them ‘Do you know I've got dyslexia?’ and they said ‘Yeah, we know that’ because they must have got records from different kinds of places when I was young and if it's been sent off and it's here and everywhere they said ‘I've got the notes, I know what you are and what you've been through’ and stuff like that.”* (Line 209)

Carrie could not recall having told the GP and was unable to substantiate her belief that her GP did in fact know. Nevertheless she claimed that her GP *should* have her literacy difficulties recorded on the electronic system:

*“You see they have got it on the computer so they have got all the information there so they should have it all on the computer, the doctors’.”* (Line 291)

#### **6.3.1.1 Revealers and stigma**

Many of the participants in this group appeared to be aware of their stigma potential and this may have had an influence on whether they actually did disclose. As mentioned in the previous chapter, participants who professed to be completely open sometimes revealed their low literacy in ways which could be considered to be covering. Stevie and Fraser both stated that they told people about their dyslexia so that they would not assume that there were other reasons for their difficulties. Moira claimed that she suffered low confidence

rather than low literacy although her account suggested that she may have both. Several of the other Revealers, had experienced stigmatisation or a sense of being different from their peers at school although they did not describe feelings or experience of stigma in adulthood. Although the Revealers were categorised as such because they had stated that they would be willing to disclose, few reported having explicitly revealed their low literacy to healthcare staff.

### **6.3.2 Concealers**

Participants who declared that they did not want anyone to know about their low literacy I categorised as Concealers. Six of the 25 interviewees were categorised as Concealers (Table 5). Clearly, participants had had to reveal their low literacy in order to engage with help at the Adult Learning Centre, and for some, but not all, one or two other people had had to be told, for example, in an unavoidable situation at work. Many of the Concealers stated that they would not acknowledge their low literacy if they were asked if they needed help with literacy activities or if there was an opportunity to having their low literacy recorded anywhere.

Some participants in the Concealers group suggested that they believed it might be helpful for healthcare professionals to know about their low literacy but their strong desire for no one to know about it was a barrier to disclosing. Non-disclosure was not confined to healthcare staff. Some of the Concealers had not told their close family members about their low literacy.

#### **6.3.2.1 Concealers and stigma**

All of the Concealers described having experienced felt or enacted stigma in social situations and all had, in their interviews, referred to avoiding situations where their low literacy would be revealed and where they would be discredited. Examples of passing and covering behaviour were described by participants thus categorised.

Some participants, such as Barbara, indicated clearly that their non-disclosure was directly related to their anticipation of stigmatisation by healthcare staff:

*“They [healthcare staff] judge people on your appearance and what you give them. On the appearance, fine, on my speech, fine. When they look at a paper, they must think, ‘God she’s ....see that, she’s like that, wouldn’t have expected that of her.’”*  
(Line 417)

### **6.3.3 Limiters**

Participants who claimed that they disclosed their literacy to some, but not all, others for various reasons, I categorised as Limiters. Ten of the 25 interviewees were categorised as Limiters (Table 5).

Participants categorised as Limiters reported that they were prepared to disclose their low literacy but that the number of people to whom they disclosed was limited in different ways and for varying reasons. In particular, many of the healthcare staff with whom Limiters had contact featured in the group of people to whom they reportedly did not disclose.

For some participants in this category, the limitation on their disclosure activity was that they reported actively selecting people that they would tell, but decided that there were others that they did not want to know about their low literacy. In these cases, their criteria for disclosure would appear to be complex and participants were mostly unable to describe these criteria. Rather they stated that they decided at the time of an encounter whether they considered that it would be appropriate to say anything about it.

Those who did reveal their low literacy to some healthcare staff most commonly mentioned their GP in particular. Historical relationships and being known by their GPs may have been associated with the anticipation of a more accepting attitude and may have influenced participants’ apparent higher likelihood of revealing their low literacy to their GP. Most

Limiters reported that they would hide it from some or all acute and specialist care staff; and GP locums.

Some participants in the Limiters group claimed that the barrier for them was in the telling rather than the selection of whom to tell and this was what limited their disclosure activity. Several stated that they would not mind others knowing about their low literacy, for example, that they would tell their GP but it hadn't come up. Other reported limitations were that participants: didn't know how to bring it up; would like to be asked; or otherwise held back for some reason. These limitations were declared by some people who had disclosed to one or more healthcare professionals but they stated that they would disclose to others if their identified barriers were removed.

Although Carol reported that she had told her GP, this had been in a situation when she had reportedly felt that she had no other option:

*"I had to fill out forms and that, so I told them..... .. I couldn't read it and I was like 'Oh no.' I had to hand it back before I left. I wouldn't have said anything if I didn't have to hand it back"* (Line 105)

Carol stated that she did not have the confidence to bring up the subject of her low literacy and she described avoiding disclosure when she was in hospital after having given birth to her child. She stated that her experience with other children in her close family had meant that she was not reliant on healthcare staff or written information to learn how to care for her baby. She also reported enlisting the help of her family at visiting times to complete any necessary forms. With these coping strategies in place, her low literacy was not an issue and Carol was able to avoid telling anyone.

*"Yeah, I just kept to myself in the hospital as well. Just sat and done what I had to do with [daughter]..... "* (Line 153)

### 6.3.3.1 Limiters and stigma

Again, most of this group described having experienced felt or enacted stigma and although their reported position was one of requiring to find the right time or words to be able to reveal their low literacy to healthcare staff, their accounts suggested that they may anticipate stigmatisation as a result and this may, in some cases, add to their reported constraint. Not knowing how to bring it up may be associated with not being sure of what the other persons' reaction might be. Indeed, some would appear to balance the prospect of stigmatisation against the perceived benefit of disclosing their low literacy in certain situations. Ralph demonstrated his perception of stigma potential, describing his feeling that there was "*less of a stigma*" at the Adult Learning Centre. Although he also acknowledged his perception of there being the potential for stigmatisation in revealing his low literacy, he reported that his multiple appointments and ongoing self-care activities to manage his long term condition tired him and he reflected that if healthcare staff were aware of his dyslexia they would be more able to provide appropriate support. This consideration did not always result in disclosure, however, and Ralph stated that he decided at the time of each particular encounter:

Ralph: "*Depends on whether I feel comfortable enough to tell them [healthcare staff] or not comfortable enough to tell them.*"

Interviewer: "*Does that depend on you or on them?*"

Ralph: "*Well, how they are, bit of both really, how I'm feeling and how they are, you know...*" (Line 431)

Margaret reported having suffered both felt and enacted stigma from childhood and throughout her working life. Her diagnosis of 'probable dyslexia' would appear to have allowed her to have a condition to which she, herself, could attach her low literacy instead of being labelled as stupid or feeling that she was stupid. Nevertheless, her stated constraint in revealing her dyslexia was that she needed to be able to trust other people not to consider

her to be or treat her as if she was stupid. She stated that she would tell her GP now but that it hadn't come up. In this way, Margaret would appear to limit disclosure both because the subject of her low literacy had not come up and because she needed to trust people and so would be likely to selectively disclose even if the barrier of how to disclose was removed.

Others in the Limiters group stated that it hadn't come up or they did not know how to bring it up. Sometimes, healthcare staff, doctors in particular, were identified as a group that were more difficult to tell and this may be associated with reasons of unfamiliarity or potential difficulties added to having to discuss an embarrassing or complex medical condition or both: Karen reported that she did not know how to bring the subject up with the doctors she saw at the hospital for her ongoing condition:

Karen: *"....I don't know why cos I tell everybody else now. But I just couldn't."*

Interviewer: *"So when you tell everybody else, who do you mean?"*

Karen: *"Like the people at my work and my friends, they all know as well, but like..... I don't know if at the hospital it's just because I don't know the person that well to have this big huge conversation with them. It's awkward enough speaking about what we're speaking about, never mind telling him about something else"* (Line 96)

Nevertheless, Karen's later comment demonstrated her perception of *stigma potential* when it came to disclosing to healthcare staff:

*"They [healthcare staff] could treat you differently, and not in a nice way. They could look upon you as if you're stupid, you don't understand what I'm telling you."* (Line 270)

This expectation was reflected in other accounts. Participants did not anticipate any change in their clinical treatment if they revealed their low literacy, but feared staff would judge them badly, look down on them and be patronising:

*“..... they speak to you like you’re three. Then they wouldn’t leave you alone. ....  
and then they’re kinda like as if you can’t do nothing for yourself” (Katy, line 387)*

Katy suggested a strong anticipation that she would be stigmatised and patronised if she revealed her low literacy. The deciding factor in categorising Katy as a Limiter rather than a Concealer was that Katy had disclosed her dyslexia to some healthcare staff, for example, her GP who had known her for a long time and to her midwife, reporting that she felt that was necessary because of all the information and paperwork involved at the antenatal stage.

Katy appeared to weigh up the risk of being stigmatised or patronised against the benefits of disclosure in a particular situation. She reported having experienced unhelpful behaviour when she had asked for help without disclosing her dyslexia. She described the response she received when she requested assistance with bathing her newborn son:

*“... you’re saying ... ‘Could you show me ... cos I’m not too sure’ and they go ‘Oh we’ve already gave you a leaflet.’” (Line 382)*

Katy’s reported experience highlights the potential for healthcare staff to be unaware that leaflets may not be appropriate for everyone or to assume that giving a leaflet to a patient is all that is required. Katy described her reaction to such a response:

*“You’re not going to turn round and say ‘Well I’ve got dyslexia’ because they’re moanin’ already” (Line 385)*

The use of the word *“already”* suggests that Katy believed that the disclosure of her low literacy would be a problem for them. If she disclosed she was going to give them something else to *“moan”* about and in this situation it appeared to be this anticipated reaction that she wanted to avoid.

In a similar situation, Pauline described covering behaviour when she declared that she would rather be considered by healthcare staff to be unco-operative than reveal that she had difficulty with writing or filling in a form. Such covering could potentially lead to stigmatisation



for a different reason. In this group of participants, it is also evident that a perception of stigma potential and the desire to avoid stigmatisation played an important role in their disclosure management and many of the restrictions would appear to be based on the anticipated reaction of healthcare staff.

Among those who had disclosed to one or more healthcare professionals, no one reported a negative response as a direct result of their disclosure and some participants reported a supportive response.

As stated previously, these categories were constructed according to the *reported* attitudes towards disclosure and ways of managing situations in order to reveal or to avoid revealing low literacy to healthcare staff and others. Comparing people's stated position on disclosure with their reported experiences and behaviours, it became apparent that overall, few people, including among the Revealers, had explicitly revealed their low literacy to any healthcare professionals and the scale of their concealment was potentially far greater than they themselves recognised.

Feelings of stigma or a perception of the potential for stigmatisation were often reported in accounts of healthcare situations. Stigmatised individuals face uncertainty over their status and are never sure of how new acquaintances will view them or whether they will be rejecting or accepting. Anticipating which of these attitudes healthcare staff will display appears to influence people's criteria for deciding to reveal their low literacy or not. Non-disclosure or selective disclosure in healthcare situations were reported by Limiters and Concealers in particular as having been directly influenced by feelings of stigmatisation and the anticipated response of healthcare staff. Many participants did not perceive that it might be helpful for healthcare staff to be aware of their low literacy.

### **6.3.4 Perceptions of advantages of disclosure of low literacy to healthcare staff**

I asked participants specifically if they thought it was important for healthcare staff to be aware of their low literacy, and their responses suggested that few perceived that there may be a reason to disclose.

There would appear to be a difference between being willing to reveal and perceiving a reason to or advantage in revealing low literacy. Although Yvonne reported that she was happy to disclose, she commented:

*“I’ve never discussed it with my GP..... I would do, but I don’t know what he would recommend or nothing for that, so I’m not sure”* (Line 209)

Yvonne thus did not perceive making her GP aware of her low literacy as potentially advantageous in a health context since it was not something he could treat. Carrie, on the other hand, did identify an advantage in healthcare staff knowing but again, this was not related to health benefits. She expressed the opinion that it made a huge difference if doctors and nurses knew about her low literacy, so that they could help her to spell.

Some people who said that they had or would disclose their low literacy, suggested that it was important that a doctor should know, and that both sides gained from the knowledge. This was discussed in the focus groups:

*“Generally, being as transparent as possible where health is involved is pretty important, for your own benefit and for those people that want to help you”* (Jason, Focus Group 1)

Others cited non-disclosure as a safety issue:

*“Yeah because if you take your medicine wrong it could do damage or you might not get the right amount and it might not work.”* (Debbie, line 110)

Margaret agreed that not revealing low literacy may be a safety issue but rather than addressing this through disclosure, she viewed this as a training need for healthcare staff:

*“But it is a nationwide thing. It needs to be trained nationwide. It’s something... and it does affect a lot of medical.. because if they can’t read their medicines then god knows, they could be killing themselves.”* (Line 704)

Disclosure was perceived to have taken place in several different ways.

### **6.3.5 Ways of disclosing low literacy: explicit, implicit or assumed**

Most participants reported finding it hard to disclose low literacy to healthcare professionals, confirming that there is a hidden population of people with low literacy, particularly in relation to healthcare staff. When asked how disclosure actually took place, participants indicated varying ways of revealing their low literacy, along with some apparent assumptions and beliefs about what had been communicated and what was understood by healthcare staff. I identified three forms of disclosure: explicit, implicit and assumed.

Very few people reported that they had explicitly told one or more health professionals that they had dyslexia or difficulties with literacy activities. Ralph reported that he had found this easier more recently and had told some healthcare professionals explicitly, saying:

*“Look I have problems with.. I’ve got dyslexia, could you please help me”* (Line 447)

A few participants reported that they had disclosed their low literacy but from their description of what was said, the manner of their telling may have implied that they had some problems associated with literacy but this was couched in language that did not describe the situation explicitly. For example, Gordon stated that he had told his GP about his low literacy in this way:

*“I said to him ‘It’s just a case of just...I know what the situation is, sometimes you’re able to cope with bits and pieces, other times when you’re...it can be a bit of a struggle’” (Line 481)*

More commonly, knowledge of the patient’s low literacy on the part of the healthcare professional was assumed. In these cases, participants declared that one or more healthcare professionals knew about their low literacy but they were unable to describe how they had revealed it. Assumed disclosure, or knowledge of the participant’s low literacy, appeared to feature in two different contexts.

Firstly, when there was history and familiarity between healthcare professionals (mainly GPs) and patients. For example, Carrie stated that her GPs were aware of her low literacy *“because they know all that anyway”* but when asked about telling them, she could not remember the actual conversation, asserting:

*“I probably did tell them at some time.” (Line 16)*

Disclosure was assumed secondly, when a healthcare professional was associated with others who were aware. The belief that this knowledge had been shared was strengthened when the professional met the participants’ needs for support:

*“Vaccines and stuff? My health visitor is quite good, cos she explained it all, but then that’s my GPs so they know. .... I think she knows, though cos like I was quite good with my health visitor, we spoke about stuff and whatnot so I think she knows anyway. She explains everything.” (Karen, line 557)*

In spite of Karen’s statement that they *“spoke about stuff,”* this did not include a recollection that she had explicitly revealed that she had dyslexia.

The disclosure management strategies and associated fear of stigmatisation appeared to be a central feature in many of the identified links between low literacy and poor health, particularly in accessing and benefiting from healthcare services, and in carrying out self-

management activities. These findings are presented next, addressing each of the research questions in turn.

#### ***6.4 Research Question 1. What are the perceived and experienced pathways between low literacy and poor health, as evident from the accounts of people with low literacy?***

Participant accounts highlighted that there were three main ways in which low literacy can impact on health, in addition to the effects on their social and mental wellbeing of the low literacy itself and of the associated stigma described in the last chapter. The three main ways were through: impeding access to and engagement with health services; threatening the integrity of clinical consultations; and hampering self-care behaviours. These are discussed separately below.

##### ***6.4.1 Impeding access to and engagement with health services***

Low literacy had made it hard for people to use written information associated with accessing health services, including appointment letters and directional signs in the hospital environment. Some participants also voiced negative perceptions of the qualifications and capabilities of healthcare staff and a poor understanding of how the health service operates, leading to low faith in some of the services. These aspects are included in the broader definitions of health literacy, such as understanding services needed or navigating the healthcare environment.

###### ***6.4.1.1 “Such a lot of words”***

Several people reported difficulties reading and understanding letters from health services:

*“... when you get letters from the doctors, sometimes it’s very hard to understand them cos they put such a lot of words down and you’re going, ‘What’s that saying?’”*

(Marion, line 9)

The amount of text on written communication from health services also appeared to cause problems. Some participants reported that they were only able to pick out parts of their hospital appointment letters:

*“The date and where it is. That’s what I tend to read, the date and the time and... well I only really get from one place so I tend to know where it is. Or the date, the time and the ward because that’s like the bolder standing out words”* (Karen, line 625)

And, as Karen went on to describe, other instructions were sometimes missed, resulting in being unprepared for consultations:

*“.....I wouldn’t have read it. Cos I’ve been to the hospital a few times and they’ve been like ‘Oh you were meant to bring a urine sample’ and I was ‘Oh I didn’t know’..... cos I just read the date, the time and the ward”* (Line 638)

Some participants reported that they could not read or understand even simple information leaflets and often ignored and discarded them without looking at them. Other written information was viewed as problematic.

#### **6.4.1.2 Hospital signs that are “gibberish”**

Visits to hospital were often described as stressful because of difficulty reading signs and several participants reported having become lost in the local teaching hospital:

*“Half of [the signs] are gibberish, because like you go down that one and it’s signed but then you go past, it says go that way and you go it and then it’s not signed at all. You thought the signs would be, and then you’ve got to go downstairs sometimes, but it doesn’t tell you, you just go along that way. It’s actually got it on the door, so you’re not like, thinking, looking at the doors. You think the sign’s up above you or something, but it’s not, it’s on the door to go downstairs”* (Yvonne, line 121)

Yvonne's description suggests that the difficulties with signs may not be confined to those with low literacy and this was put forward by others:

*"It's bad enough for anybody to find their way around [local teaching hospital]"* (Fred, Focus Group 2)

Similarly, Iain pointed out:

*"Signs may be adequate under normal circumstances but when people go to the hospital, they may be upset, or it's very busy, you go along with the crowd."* (Focus Group 2)

Many of the participants said that they were unwilling to ask for help with directions. However, some participants who reported that they did ask, stated that the verbal directions given were often difficult to follow. Complicated verbal directions requiring the recipient to process a series of instructions were reported as having been given to participants when they had had to go to a different department following or during a clinic visit, for example, for an X-ray:

*"And they go 'Right go along the corridor turn left turn right turn left, down the stairs, up the stairs then take a right' and you're like 'What?'"* (Katy, line 467)

It is likely, that while navigating healthcare environments, such as the large teaching hospital referred to in this study, may be difficult for many people, those with low literacy will be particularly challenged because of the various and complex literacy activities required. Understanding how health services are delivered was also an issue for some.

#### **6.4.1.3 "You feel like you're getting second best"**

Participant reports suggested that some may have a poor understanding of and associated low faith in the abilities of healthcare staff who deliver acute care and this may be considered to be one of the wider aspects of health literacy. Participants complained that they were

often seen, not by the consultant whose clinic they were attending, but by another doctor. This was not generally considered to be satisfactory and associated comments included that it made them *“feel like a guinea pig.”*

Participants declared that if they were booked in to see someone that is who they should see, some viewing the alternative consulting doctor as a *“dogsbody”* or similarly less authoritative person. Discussion in the focus groups elicited agreement from others and suggested that some participants made the assumption that doctors who were not consultants were not suitably qualified:

*“I know they have to do training but you feel like you’re getting second best”* (Susan, Focus Group 1)

Similarly, in relation to the ‘Out of Hours’ arrangements whereby general practitioners operate a rota system to provide consultations for people referred, mainly through NHS24, for urgent primary care treatment outwith normal surgery hours:

*“I can’t see my own doctor at his own surgery but he’s doing Out of Hours when he should be looking after his own patients.”* (Iain, Focus group 2)

In a similar vein, Iain gave an example of a specialist who treated his son for a relatively rare congenital condition. The specialist worked all over the country and Iain declared:

*“I don’t know how he could travel all over and not be that tired that he would make mistakes”* (Focus Group 2)

In his individual interview, Harry indicated that he blamed his perceived poor service from his dentist on his lack of knowledge about his entitlement which, he said, prevented him from being able to ask for the treatment he needed. This was in spite of his payment into a dental plan which he regarded as compulsory:



*“....like my dental practice, I dinnae feel I get anything from it but I’m paying every week for it cos I’ve got to.. I dinnae ken ... [Wife] is doing all that side of it like but I’m ha’in’ to pay and I’m no getting any better treatment for it..... you totally trust them and if he’s no trustworthy with you then you dinnae get and if you ha’e the confidence to speak oot and you ken what you’re talking about, then you get what you’re entitled to, if you dinna, you just dinna get. My teeth are all falling away here, chipping away and .... if you dinnae ken what you’re askin for or talking about in the first place ... . Other people seem to get everything they want whenever they want and not me... That’s the way I see the health service anyway, it might no be like but I see it deteriorating cos it’s not there for you” (Line 1006)*

These comments about the health service may indicate a lack of perception among participants that they get good care; or lack of respect for or from healthcare professionals whom they reportedly viewed as following their own interests and providing a less than satisfactory service. Such lack of understanding may discourage access or compromise potential benefit from health services and clinical consultations.

#### **6.4.2 Threatening the integrity of clinical consultations**

As already shown, patients may arrive unprepared for a clinical consultation when they have been unable to read instructions included in their appointment letter, such as to bring a urine sample. While clinical consultations themselves do not generally involve the performance of reading or writing on the part of the patient, many participants associated their low literacy with difficulty in spoken conversations with healthcare staff, both because they struggled to understand what was being said and because they felt staff related to them poorly. As already described, participants reported their unwillingness to disclose their low literacy to many people. In their accounts, participants variously described examples of hiding their low literacy; feigning understanding; and not asking for help in a healthcare context, so that

communication and relationships with healthcare staff were likely to be compromised and their engagement in clinical consultations limited.

#### **6.4.2.1 “Big words that doctors seem to make up”**

Difficulty in understanding what was being said during consultations was often attributed to the language doctors used, considering it on a par with “solicitor’s gobbledegook.” Participants used terms such as “big fancy words,” “twenty four letter words” and “doctor terms” to describe the language that doctors used in communicating with them.

Karen described a conversation she had had at work about a word she didn’t understand and related that to the language of doctors:

*“... it was that one about the woman who had had 8 kids and it was in the paper and I was like “What is that big word” and [work colleagues] were all going on about it and I was like ‘But what does that mean?’ oblivious to me as to what this word means..... and [work colleague] was like ‘She’s just had 8 kids’ and the other girl went like ‘Yeah because an octopus has 8 legs’ (laughing) I was like ‘Yeah, get you now.’ But like that word, that’s obviously a doctor’s word, that’s obviously like, that’s what I call them.” (Line 754)*

Again it was suggested that people other than those with low literacy may also struggle, in this case, to understand doctors’ language:

*“...cos it’s these big stupid words that, to me, a normal person wouldn’t know.....cos it’s not just people with dyslexia that can’t understand all these big words that doctors seem to make up” (Karen, line 764)*

Karen’s point may well be valid but because of the behaviours of people with low literacy in hiding their low literacy, feigning understanding and not asking for help, healthcare staff may be under the impression that the patient in front of them is taking in what they are being told.

Some participants thought that doctors made no effort to help them understand:

*“.... and [hospital consultant] was ‘Blah blah blah’ and he knew fine I didnae have the foggiest idea what he was talkin’ about”* (Harry, line 591)

Participants also felt that many healthcare professionals regarded themselves as better than patients, which made the relationship in consultations unequal. Some, however, indicated a recognition that these perceptions could be exacerbated by the way their low literacy made them feel about themselves.

*“I think it’s about how I feel. I think it’s how I feel myself, I just feel embarrassed..”*  
(Louise, line 226)

Participants reported fewer communication difficulties with GPs than with other healthcare staff. Relationships with GPs were discussed in Focus group 1 and comparisons made with other healthcare professionals such as those in acute hospital settings. Participants expressed a preference for seeing their own doctor and they were less happy when they had had to go to one of the other doctors in the practice. This was a reiteration of what many of the individual interviewees had said. Participants in Focus group 2 expressed the view that they could never get appointments with *“the doctor who is so good and explains everything.”* Consultation with one’s own GP was described as *“more personal.”*

In general, GPs were described by participants as more caring, friendlier than other healthcare staff, and more likely to explain things and treat them as equals. GPs were also more likely than other healthcare professionals to be aware of participants’ low literacy and this may be influential in some cases as to how much explanation is provided. Better relationships and communication with GPs than with other healthcare staff were also reported by participants who stated they had not disclosed their low literacy to their GP. Their accounts suggested that this may be linked to the history and familiarity of the relationship.

Most of the participants in the study had had the same GP for a long time, many since they were born. This is fairly typical in Dundee, and sets the city apart from other areas in that people very often do not change their GP even when they move to another part of town. In these cases, the GP may or may not be aware of the actual literacy needs of an individual but they may be aware of their need for support with understanding and their requirement for simple explanations. Other healthcare staff tended to be viewed less favourably by participants.

#### **6.4.2.2 Participants' labelling and stereotyping of healthcare staff**

Participants' anticipation of stigmatisation and stereotyping was perhaps influenced by their own labelling and stereotyping of others. Several participants demonstrated stereotyping in their comments about healthcare staff, particularly doctors. As well as the consensus among many participants, already mentioned, about the actual language used by doctors, some made reference to other aspects of communication and relationships with healthcare staff:

*"... doctors and nurses, not so much nurses but doctors, that they, they're just like robots in a way if you know what I mean. You know, they've got one set way of speaking to people."* (Ralph, line 95)

Others spoke of lack of time or lack of empathy being the reason for poor communication. Sandie's comment on lack of empathy also appeared to express the view that doctors are aware that they are using language that patients do not understand:

*"..... you need to spend a little bit more time, you are a doctor, you are still a human being, you have got to think of other people, you have got to come out of being a doctor and think of that as my mum or that was my dad and I didn't understand what the doctor said I would want them to speak in a way they understood."* (Line 500)

Many participants described healthcare staff as being judgemental or looking down on people:

*“..... because the doctor thinks they’re better than you”* (Megan, line 220)

A few participants appeared from their comments to have made the assumption that healthcare staff would not have knowledge and/or understanding of dyslexia:

*“I think doctors and nurses need to understand more about disabilities than just hearing of them, you know what I mean.”* (Katy, line 313)

Margaret also thought that her doctor may not know what dyslexia was and so declared that there may be no point in telling him:

*“Like I say, I wouldn’t have asked my doctor, but I didn’t know if he knew about it. So if I started coming out with dyslexia and he didn’t know nothing about it then we’re both sat there like two plum duffs.”* (Margaret, line 566)

Clinical consultations were also potentially of reduced benefit because participants did not access support they may need with obtaining and understanding relevant information.

#### **6.4.2.3 Not asking for help for fear of being discredited**

Although participants often recognised they had a poor understanding of health issues and treatments, fear of disclosing their low literacy frequently appeared to prevent them from asking for help or further explanation in clinical situations. For some, asking for help was synonymous with disclosing. Others, however, asked for help without giving a reason and they did not perceive this as disclosure. Katy described buying over-the-counter medicine thus:

*“I’m asking for it and they’re like ‘Oh that’s there’ that wouldn’t bother us.”* (Line 228)

It could be argued that being unable to find something on a shelf is less likely to be linked to literacy activities and thus Katy was able to ask where to locate a particular medicine without

disclosing. In general, however, if a situation involved directly performing a literacy activity, such as completing a form, it would be more difficult for someone to get help without disclosing. Marion speculated what she would do if she was given a form to complete by a doctor at the hospital and was struggling with it: *"I would just say I find it difficult to fill in forms."* In Marion's example, disclosure of low literacy is the route to asking for help. It would appear that it is not just certain people to whom those with low literacy may disclose, but how or what help is requested may also be a deciding factor in whether disclosure takes place simultaneously.

Participants did not demonstrate making this differentiation, however. They commonly reported that they did not ask for help at all to avoid disclosure; they stated that they did not indicate to healthcare staff that they did not understand something; and many described how they implied that they had understood verbal information by nodding or verbally declaring their understanding.

The majority of participants had not revealed their low literacy to one or more clinicians whom they were consulting and the most commonly reported reason for this was because of the anticipated response of the clinician. Although no one gave examples of stigmatisation or discrimination by a member of staff in the healthcare environment as a direct result of disclosing that they had low literacy, the expectation of such was reported as a strong influence on people's decisions not to reveal their low literacy. Barbara illustrated this in her explanation of why she would not ask for help:

*"How could I put it? It's the look. How would I explain to them, 'I'm sorry, I can't spell.' I can't, **no way, no way. I couldn't do it. I couldn't do it.**"* (Line 129)

Margaret reported that she regularly implied that she understood what she was being told by the doctor:

*"When I go to the doctor's ... where one bit I would have just said 'Yeah, oh yeah' then come out and thought 'I've got no idea.'" (Line 118)*

Others demonstrated similar passing behaviour to Margaret's when they described indicating that they had understood what they had been told in clinical consultations:

*"...they never explain anything properly. It's always their own big words and I just say, 'Uh hmm', 'Yeah, okay' and I go home and I'm like, 'I don't know what that meant'"*  
(Megan, Line 79)

Not everyone was prevented from asking for help because of fear of stigmatisation and again, there was a suggestion that some people weighed up the risks against the benefits of disclosure. For example, Sandie stated that she had previously concealed her low literacy but that this had caused her to panic, so she now felt that it was more important to understand healthcare advice than to worry that someone may think she was thick

*"I'd ask for help, I don't mind if they think oh she's being a bit stupid or a bit thick, I am just like well I need to understand it."* (Line 186)

Several participants identified that they would feel stupid or silly if they asked questions so they declined to ask anything during their clinical consultation. Some had associated asking questions in adulthood with the humiliation they had experienced from asking questions at school.

Clinical consultations were also reportedly affected by fear that participants reported feeling for various reasons.

#### **6.4.2.4 Clinical engagement overshadowed by fear and panic**

Panic and fear reportedly featured heavily in clinical situations with the potential to reduce both engagement with the clinician and benefit from the consultation.

Fear was reportedly felt in relation to being judged to be a bad parent; or not understanding clinical procedures or results.

Fear of being considered unable to take care of their children properly because of their dyslexia was mentioned by several of the young mothers. Katy described her fear thus:

*... when something bad does happen or there's an accident or something when you first go to the doctor or the hospital you are, you're sittin' there thinking like 'Do I tell them do I not?' but you're scared to in case then they twist and they think 'Well this could have happened because you've done wrong.'"* (Line 588)

Katy further suggested that *"bells start ringing"* if you mention dyslexia to a doctor, a response which was viewed as having implications for the patient.

Some participants who were young mothers reported a perception that professionals criticised them because of their youth anyway, suggesting that, as young mothers, they possibly belonged to an additional potentially stigmatised group.

Jack underwent a procedure which made he said him feel *"scared as hell"* because he didn't understand what was going on. He reflected also that viewing the results, in his case, a scan that he had undergone, *"scares the life out of you."* Several participants expressed their fear in such situations and their reluctance to reveal low literacy, shown earlier to be associated with not asking questions or requesting clarification during clinical consultations, may have exacerbated such fears. It would appear, however, that the fear of stigma or being discredited may outweigh the fear caused by the procedure, thus they were likely to experience reduced benefit from the consultation.

Some participants' accounts suggested that the benefits of clinical consultations could be compromised by their actions to avoid revealing their low literacy. For example, Barbara described what happened when she was given a form at a dental surgery:

*"..... I couldn't spell it. It was a complete, I just went, 'You know what, I'm going to have to go. I'm not feeling very good. I'll come back, I will come back' and I grabbed [the form] and ran out"* (Line 154)



Barbara further described how exposure or fear of further exposure of her low literacy would affect a clinical consultation:

*“If I was in a doctors, and I just made a mess of the form and just say I’ve had to put it in, and I’ve seen him reading that form, ....it would be very withholding, and I’d be more concentrating on, ‘He must think I’m stupid. He thinks I’ve made a real mess of that. He’ll be thinking I’m a let down. Oh God, what is he thinking of me?’ and I wouldn’t be concentrating on what he’s actually looking for..... I would want out the whole situation..... knowing it’s an error, it’s a mess, then I’d be distracted with that form. That would cause me a lot more anxiety. Because you’d be scared to get another form to fill in or you’d be scared that he’s going to say to you, ‘Could you come back and put this in writing, or could you...?’ No chance. I’d want out of there as quick as I possibly can.” (Line 232)*

She went on to reiterate what others had proposed, that is, that it would not affect any treatment but that the delivery of care may be affected:

*“I don’t think with the health board, it would stop any treatment, it would delay it because it would take them longer to find what the information they were looking, whereas if you were relaxed and comfortable and concentrating on what they were asking, then they would get a truer answer. Where if, you’re nervous and you’re pulling back and you think you’re going to get another big load of paperwork or that is my form he’s got there and he’s thinking, ‘God....,’ then you’re just going to finish it as quick as you can, short answers, just get out. ‘I don’t know,’ or ‘Yeah,’ ‘No,’ where you wouldn’t say, ‘Well, actually.....’ and be more explicit, you wouldn’t do that. Well, I wouldn’t. I’d want out. I’d want out.” (Line 268)*

The use of the term “*let down*” in the first of Barbara’s quotations above again highlighted Barbara’s perception of being able to pass as normal but having stigma potential because her low literacy was mismatched with how she presented herself to others.

Louise stated that her fear of having to write something caused her to panic in situations where this may arise. She described her participation in a clinical study in connection with a condition she suffered and getting “*in a right panic*” in case she had to write anything or fill in a form, a feeling she reported experiencing every time someone produced a piece of paper. She not only used the word but recounted the situation in terms illustrative of panic:

*“... I’m like that, ‘Oh no, they’re wanting me to write something,’ start panicking and that seems to take over you and sometimes you’re like that, ‘What was they saying there?’, because the anxiety’s took over what’s going on.”* (Line 409)

This description of panic taking over was reiterated by Barbara, who said that “*everything is just a block*” and she “*can’t think*” once the panic begins. She further reported having “*run away from situations many a time.*”

Although Jack declared that he wouldn’t ask for help or reveal that he didn’t understand something, he held the view that doctors also held back information which, if shared, would increase his benefit from the consultation:

*“...Straight from the doctor rather than it’s like a wee secret you see, it’s like a secret until he obviously doesn’t want to commit until he gets the result, you know, but he could have said that it was blah blah blah, in layman’s terms so you can understand it.”* (Line 736)

Through the potential effects of information control and poor communication on clinical consultations reported above, it is likely that opportunities for people with low literacy to receive the advice they need about their illness and its self-management, are lost. Participant accounts also suggested other effects on self-care.

### **6.4.3 Hampering self-care behaviours**

Low literacy had implications for participants' abilities to carry out the necessary literacy activities for effective self-care. Some participants acknowledged that they needed extra support in relation to self-management of health conditions. Participants reported being unable to read or understand patient information supplied with medicines, that the leaflets had too much text or too small text and some participants expressed a preference for oral explanation to ensure that they understood what was required:

*"I prefer that somebody take that wee bit more time to tell me, like, for example when I found out I had diabetes"* (Dorothy, line 114)

Several participants reported that even if they knew how many tablets they were supposed to take in a day, they did not know what time of the day these should be taken and whether, or how they should be spaced throughout the day:

*"The only problem, I couldn't know if it was morning, afternoon and night or was it just one every six hours you know."* (Bert, line 352)

Again, the word 'panic' was used frequently, in this case, to describe responses to having to self-manage their medication. Ralph reported feeling *"panicky"* if he was given a prescription for something other than his normal medication. Stevie also expressed that he panicked about managing his medication.

Nervousness and anxiety had an effect on situations where low literacy hampered the performance of self-care activities. As well as worrying about being judged by others as being unable to care for their children, some young mothers reported that they did worry about the possibility they might make a mistake such as giving a child the wrong amount of medication so that they became ill.

Ralph described the stress of coping with the literacy activities required to care for his long term condition:

*“I get very tired and it’s cos of the literacy thing trying to focus on everything that’s going on at the same time, you know, cos it all goes so fast, you know..... I find it very exhausting if I have to read a leaflet or fill out, you know, the forms that they give you and stuff like that, after a while I just think oh (sighs) and I feel kind of embarrassed that I can’t do it properly you know?” (Line 110)*

Many participants were unable to buy commonly used medicines and some participants appeared to struggle to understand what was available, potentially making the task of trying to locate medication for a particular condition more difficult:

*“I know there’s different Anadins, there’s Anadins for headaches and for backs and I could read Anadin but when I looked at the boxes, I looked for t-oo-th but couldn’t see it at all” (Bert, line 290)*

As well as written information posing problems for participants, verbal information was also reported as unclear.

#### **6.4.3.1 “I didn’t understand all what she was trying to tell me”**

In the individual interviews, low knowledge of health conditions was frequently demonstrated in descriptions of particular medical problems that people had experienced. This was sometimes related to being diagnosed with a condition that required self-care and was often associated with being unable to understand explanations:

*“When I first was diagnosed as a diabetic I found that terrible cos I didn’t understand all what she was trying to tell me.” (Margaret, line 741)*

Thus, low understanding and knowledge had a potentially compounding effect on the diagnosis of a chronic condition. The possibility that this may also make it more difficult to

cope with necessary procedures was suggested by some participants who reported attending appointments with little understanding of what was to happen, even when they could read the information that had been sent to them:

*“I could read the word ‘endoscopy’ .... I actually thought an endoscopy was down here [indicating throat] but I was told by the doctor that they're checking your stomach, see so I didn't think they were going the other way, so it was quite ‘bloody hell’, you know and you don't realise what you're gonna feel like after so it was quite an ordeal.”* (Jack, line 247)

In considering the broader definitions of health literacy, many of which include knowledge and understanding, Jack's example illustrates one way of differentiating between basic literacy skills, such as reading, and health literacy. Jack was able to read the words, so in some of the health literacy assessment tests this would pass as good health literacy. However, he had no understanding of the procedure he was about to have. Similarly, when she was pregnant, Yvonne had the relevant leaflets read to her by her mother but she said that she did not understand all of the information in them.

These issues highlight broader aspects of health literacy, the need to understand the particular language in a health context may be challenging to many more people than those who have low functional literacy. However, those with low literacy are likely to be doubly compromised with written information if they have additional difficulties with reading. Those interviewed also appeared to be unlikely to be presented with or to take up opportunities to improve their health literacy because of not asking for explanations and feigning understanding of the explanations that they were given.

## **6.5 Research Question 2. What resources and coping mechanisms do adults with low literacy employ to help them navigate the healthcare system and to carry out self-care activities?**

Some people disclosed their low literacy to a healthcare professional to improve their ability to engage with the health services they were accessing or to carry out self-care activities. Others reported memorising instructions or working out ways to measure out medication. Some coping strategies may further hamper self-care activities or compromise patient safety, for example, strategies employed to purchase over the counter medication. Many of the participants relied on family members and others for support.

### **6.5.1 “My partner has to explain it in layman terms”**

Participants often relied on family members and others to read and explain letters and other written information. Some reported bringing hospital appointment letters into the Adult Learning Centre so that their tutor could help them read and understand them. One young woman reported checking with her manager at work what time off she had booked for an appointment. Some of the reported help was through formal services but requested in an informal way. For example, some people described checking with the hospital or clinic:

*“I’d just look at the date and then phone up ..... ‘Oh this is Mrs I. And I can’t quite understand, is it Tuesday, Wednesday, the 11<sup>th</sup> of...?’ And she’d tell me...”*

(Margaret, line 199)

For many participants, when they attended appointments, more so at the hospital and less so at their GP, someone, usually a parent or partner accompanied them. The supporting person was there to help with the advice or information given during the consultation, to help with written information or in some cases to be the active participant in the consultation:

*“When the doctor turns to my partner, I am sitting there looking as if to say ‘What are you on about?’ But then my partner has to explain it in layman terms later on.”*

(Chloe, line 208)

None of the participants reported that a healthcare professional had indicated that they were aware of the patient’s particular reason for having support even when the supporting person played a significant role in the consultation, such as answering questions or discussing treatment.

Some participants viewed being accompanied as an adequate and acceptable solution while others indicated that they would prefer to be able to attend appointments alone although they did not see this as a feasible option. Karen stated that she panicked at the thought of not having someone to go with her to her appointments and so going alone was not an option she could consider, although she acknowledged that she was creating a problem for someone else:

*“I’d love to be able to go to my appointments on my own. Cos I’d like to know that I could go to my appointment without somebody holding my hand. That’s the way it feels. It feels like I’m still a kid and I can’t go to an appointment on my own. I can go to my GP on my own but I can’t go to the hospital on my own. I really just can’t. Which is horrible, cos then my mum has to take holidays off her work to come with me.”* (Line 703)

### **6.5.2 “My husband puts all my tablets in a weekly box”**

Many participants reported that they enlisted help with medication while others said that they used guesswork in relation to frequency and dosage. Help with medicines included having someone check the dose and frequency on the label; and sorting and organising tablets for daily medication:

*“My husband puts all my tablets in a weekly box, which I should do that but we’ve always done that. We’ve always had boxes where we have a week’s medicine and every week [husband] sits down and puts all his medicine and all mine.” (Line 253)*

Some participants explained that they were able to cope with medication, for example, using an inhaler, because they had been doing it from childhood and had been supported by their parents when the time came to take over the administration of their own medication.

Several participants reported memorising and implementing medication instructions given by the doctor or pharmacist. For example, Katy recounted the frequency and dosage of all her son’s medicines. Others gave examples of what colour of tablets they had to take, when and how often they took them.

A few participants described techniques they implemented to help them measure out their daily medication. Stevie reported worrying about running out of tablets and so regularly checked how many he had left:

*“... sometimes I panic and I’ll check my tablets what I’ve got left and I says ‘that day, that day, have these that day, have these that day, a couple of days from here.’” (Line 264)*

Bert reported a similar technique which he employed when he first took his medication home:

*“Well as I say I can read it now, where before, I mean I used to just like try and read it and I couldn’t cope really, I actually counted the tablets, seven days, I used to count the tablets out for seven days, ‘Oh that’s three for that day and three for that day’, and that’s all I did” (Line 343)*



For those who self-managed their medication, their coping strategies sometimes involved guesswork or behaviours which may lead to making mistakes.

Although Bert was able to ensure that he took the correct amount of tablets each day, as mentioned above, like many others, he was unsure about the timing or spacing of these throughout the day so that he resorted to guessing what time to take his tablets:

*“I just take one in the morning and afternoon and at night and hope for the best.”*

(Line 356)

Some participants who purchased commonly used medicines reported guessing which one they wanted; identifying medicine from having seen it advertised on TV; or taking along an empty packet or bottle to show to the pharmacy staff or to match to a product on the shelf.

### **6.5.3 When support breaks down**

For those who enlisted help from others, the support arrangements appeared protective in facilitating benefit from clinical contact and helping ensure adherence to medication and treatment. Support arrangements may, however, compound the difficulties posed by low literacy by promoting dependence and reliance on others, and discouraging efforts to develop and use literacy skills so that when support breaks down, problems arise:

*“.... I sat in my house with my child screaming from 6 o clock to 9 o clock waiting on her dad..... I didn't know how to make up a formula bottle because I'd just came off of breastfeeding milk ..... I couldn't understand what the bottle ... the thing said.”*

(Karen, line 796)

Margaret also described a situation when her husband was rushed into hospital. If he had had an extended stay, her reliance on him to organise her medicines may have become a problem as she was uncertain if she would have been able to do the task herself:

*“...fortunately when they rushed [husband] in [to hospital], he’d already done the medicines. If he hadn’t have done, I would have been... I would have known what to do. I know how to put ‘em in, you know, that but maybe some of the medicines I wouldn’t have...”* (Line 260)

Continued dependency was acknowledged by Margaret, in spite of her reportedly improved literacy skills and understanding since attending the Adult Learning Centre. When she was given information on a newly diagnosed condition, she commented:

*“... I will try my best to read all the information but then [husband] will help me, my husband helps me. I still sometimes rely on him, still, a bit when I shouldn’t. You know, I still.. I’ll say to [husband] ‘Oh read that for me.’”* (Margaret, line 228)

Margaret’s suggestion that she shouldn’t rely on her husband because of her increasing ability to read things for herself suggested that she felt she should be *“taking responsibility”* now that she had the skills.

Other disadvantages of relying on informal support were given, for example, relying on someone to read letters sometimes meant waiting until a convenient time to be able to establish from the letter what was required of them and this could be both inconvenient and worrying:

*“I always need to get a second person to read my letters and I might not be able to see them for a couple of days so I might get into trouble or miss an appointment”*  
(Jason, Focus group 1)

The role of others in supporting access to healthcare and self-management would therefore appear to be mainly beneficial but there are also disadvantages, not least the over-reliance on others which may discourage the development of literacy skills to carry out required activities, such as childcare. It may also reduce the likelihood of accessing formal help and support.

Some coping strategies were employed to avoid disclosure rather than as an aid to navigating the healthcare environment or carrying out self-care.

#### **6.5.4 “I’ve not got my right glasses”**

When participants were faced with a situation where they were expected to read or write, some revealed their low literacy, for example, as mentioned above, when Carol was faced with having to complete a form.

However, in similar situations, some participants avoided disclosure of their low literacy by excusing themselves from the encounter, as described by Barbara when she ran out of the dental surgery, or by giving reasons as to why they were unable to perform the required literacy task:

*“I would say, ‘I’ve got other glasses for reading’ and things like that, I’d say, ‘Oh, I’ve not got my right glasses.’”* (Louise, line 105)

The accounts provided thus gave important insights into feelings attitudes and behaviours which need to be taken into consideration along with the suggestions put forward by participants which help to answer Research Question 3.

### **6.6 Research Question 3. What kinds of changes in health service provision might improve service accessibility and health care and self-care experiences for people with low literacy?**

Participants had a variety of suggestions for service improvement, but most focused on one of two areas: simplifying communication; and facilitating or removing the need for disclosure of low literacy.

### **6.6.1 Simplifying written and spoken communication**

Participants reported that they would be more likely to use health information leaflets (including medication instructions) if they were simpler; had less text; bigger text; and used informative supporting pictures. For example:

*“... so it should have a picture of .. a person with their mouth open, or one tablet and then maybe a times 1 and then maybe in the morning so then people can identify I’ve got to take that one or if it’s night time it should be like you know two pictures...”*

(Ralph, line 274)

There was also a suggestion that it would be helpful to have a picture of a clock for each of the times throughout the day the medication should be taken. This would perhaps address the confusion some people reported about the appropriate time interval between doses.

Focus group 1 discussed the possibility of different coloured lids for medicine bottles, which they agreed would be useful for people taking multiple medications, but there was general agreement that this might make them more attractive to children and so be potentially dangerous.

Several participants suggested using colour coding to help identify different departments in hospitals. Departmental colours could be used in appointment letters, hospital signage and on lines on corridor floors to help people find their way to the right clinical areas. The focus group participants suggested that if this was not practical or affordable, identifying the different blocks of the hospital by colour and having the signs to these all one colour would help. Having a map with pictures to accompany the hospital appointment letter was also suggested as was lowering the position of the direction signs, many of which were considered to be too high to read.

Participants suggested repeatedly that their understanding of clinical information and advice could be much improved if healthcare professionals explained things in layman’s terms

rather than using jargon and medical terms. Simple ways of remembering things were favoured. One participant gave an example of the slogan *“Four is the floor”* which had been on the written information given to a family member with diabetes to help them remember the danger level for their blood glucose reading.

### **6.6.2 Ask Me3 and Teachback**

I introduced the topic of Ask Me 3 and Teachback to the focus group discussions as a potential way of addressing the expressed desire for simple explanations. As already mentioned in Chapter 3, the suggestion to implement these practices did not emerge from the participant interviews. It is unlikely that participants would have knowledge of these methods, which originated in the US and are not widely used in this country. I explained both systems to the groups.

Participants in Focus Group 1 liked the idea of making it acceptable and easy to ask the questions.

Frances: *“Sounds good.... makes you comprehend”*

Jason: *“People instil a lot of confidence in doctors but you should be the one asking the questions. The doctor is meant to be the dude that knows at the end of the day. That’s interesting to put it the other way”*

Susan: *“Yeah, people say write a list of what you want to ask when you go to the hospital but you feel embarrassed to have a list, but if there were certain questions you asked....”*

Evelyn: *“Normally you don’t like to question medical staff”*

Focus Group 2 gave a general indication that this might be a good idea but no one in the group expressed either enthusiasm for it or any particular negative feelings about it.

The Focus Group 1 discussion went on to consider the feasibility of having the answers to the three questions voice-recorded on to their mobile phones. This type of approach had previously been highlighted in the one-to-one interviews:

*“I don’t know if it was common, the surgeon, he would ask you questions and I couldn’t remember or I couldn’t answer him and what he did was, he says, ‘I’m going to tell you what’s going on’ and he gave us it in a tape. It was all recorded and he gave us the tape back to take home so I could listen to everything he was saying and anything I wasn’t sure of, I was able to write it down. .... He never asked for it, he never asked for my bit of paper or anything.....You think, oh God, I never asked that and I don’t know if he did it with everyone or he did it because of the stress and the forms or whatever, but he certainly did it with me and I got it, three times..... I thought that was, for my situation, it was just having a big weight off my shoulders that I had time to listen to what he was asking, listen to what he was telling me and what questions did I have?” (Barbara, line 197)*

In a similar vein, Frances (Focus Group 1) reported that on the day that her mother was unable to accompany her to a hospital appointment with her young daughter, Frances asked the doctor that she saw to email all the relevant information to her. She said that she was then able to show the email information to her mother who explained it and helped her implement the advice.

### **6.6.3 Facilitating or removing the need to disclose low literacy**

Participant opinions on how disclosure of low literacy might be managed were mixed and complex. Those who had difficulty actually telling someone suggested that healthcare staff could offer help (for example, with the completion of forms), or ask about literacy along with other questions or as part of any initial forms that had to be completed. Some participants suggested that recording low literacy in medical notes would prevent them having to disclose repeatedly. The idea was considered by some to be an acceptable one because, as with

other information in medical notes, it would be confidential. However, it was also put forward that doctors don't read the notes and that important information is not always communicated to other healthcare staff.

Recording of literacy needs in medical notes was not viewed as an acceptable service response for most participants, particularly those who reported that they would rather not disclose their low literacy to healthcare professionals. Avoiding the need for disclosure was preferred. Pharmacies were frequently cited as good examples where routine practice is to offer help and explanations to everyone. The universal aspect of any assistance offered was deemed by participants to be of central importance so that those with low literacy were not identified and stigmatised. Other suggestions included:

- ❑ Sending forms out for completion before an appointment
- ❑ Avoiding paper forms by using electronic methods of collecting information before clinical consultations

A discussion by Focus Group 1 resulted in suggestions as to how the use of electronic systems could be adapted for ease of use by people with low literacy. Participants discussed the possibility of having touchscreen computers with spoken menu options and headphones for privacy to gather patient information. They acknowledged that there would be a cost involved in this but proposed that it could be timesaving at a busy clinic. The practicalities of logging in were discussed and the use of a unique identifier (such as national insurance number, postcode and address finder) which could be provided on a keyring, was deemed to be the best way for people to access or provide their own information. Other potential issues such as people's fear of technology and the reality of being able to provide all the necessary information without writing some text were acknowledged. Security issues in terms of people putting in someone else's number and accessing their information were not mentioned by participants in the group.

#### **6.6.4 Disclosure management and the service solution – no one size fits all**

Many of the perceived and reported barriers to engagement with services or situations which may threaten the integrity of clinical consultations or hamper self-care activities were linked to disclosure management in relation to low literacy. Similarly, some of the suggested service solutions may work to a greater or lesser degree depending on whether people are prepared to reveal their low literacy, for example, in response to service practice that would facilitate disclosure. Colour coding in hospitals, which was suggested as a means of helping to find the way to specific departments would be available to everyone but many of the other potential service solutions were likely to receive mixed responses from those with low literacy.

I returned to my categorisation of participants according to their reported disclosure management strategies to help speculate what might happen if some of the potential changes, drawn from participant accounts, were put in place.

Intuitively, Revealers should be willing to engage with any service responses regardless of whether this requires disclosure or not; Concealers may be expected to be unwilling to engage with initiatives that would require disclosure; and Limiters do not necessarily have an intuitive stance, as they may or may not respond, depending on if their disclosure criteria are met. On examination of the categories and the accounts of participants, judging the likelihood of engagement with service responses may not be so simple.

Improving spoken and written communication was clearly considered by participants to be of potential benefit to people with low literacy. Leaflets with simple language and supporting pictures would reach a wider audience and possibly make the need for them more acceptable. However, if they were to be made available as an option, rather than as the only option, Concealers would probably not respond and Limiters may or may not take up the offer. Limiters who were reportedly constrained by not knowing how to broach the subject of their low literacy or who were waiting to be asked about it would appear likely to respond if



healthcare staff were to offer help with literacy activities but again, Concealers would probably not respond as they may view this and the simplified written information as enforced disclosure.

Concealers would also be unlikely to accept having their literacy needs flagged in their medical notes. Some Limiters may not respond to a note in their medical records if they would prefer to remain in control of the information and selectively disclose; and some would potentially welcome having their needs highlighted in their notes.

It would follow that Revealers would welcome any of the proposed changes to improve communication; record literacy needs on medical notes; offer help and support; and provide alternative formats for information, but this may not be the case.

Stevie's stated belief that everyone in the health service was aware of his low literacy indicated something about his understanding of how the NHS system works and how much is communicated across departments, between primary and secondary care and across regions. Nevertheless, for Stevie, asking for or receiving help did not automatically follow either his having disclosed or the assumption that staff were aware of his literacy level:

*" .... because I like trying to do things myself ..... I have tried filling [forms] in and I have asked them can you go over it ..... "* (Line 225)

From Stevie's account, the need to take the initiative to get help always seemed to be on his part, which may be the case because it was unlikely that all the information about his 'dyslexia' was as commonly understood among healthcare staff as he believed; or perhaps his belief that they were aware of his needs allowed him to be in control of what help he enlisted. It also raises the question of whether even Revealers would engage completely with potential changes to service provision.

Katy, who was categorised as a Limiter, appeared to have a different view of communication across the NHS and apparently did not believe that telling one person meant that this would

be shared, She further expressed the view that telling everyone individually was neither practical nor desirable:

*“.... you’d spend your whole life saying ‘By the way I’ve got dyslexia,’ two minutes later ‘By the way I’ve got dyslexia,’ ‘By the way, I’m dyslexic’ you know? If you had to tell everybody, do you know?” (Line 480)*

This highlighted an important point about how often people might potentially have to disclose their low literacy and again, even Revealers may not recognise this or be prepared for it.

Most of the participants indicated that they did not find it easy to reveal their low literacy and it would seem more appropriate for healthcare staff to take the initiative in exploring people’s needs. It may be necessary for staff to ask a direct question to elicit disclosure of low literacy. If such opportunities were provided in a sensitive way, Limiters may also respond to this. Ralph was categorised as a Limiter and his comments on disclosure suggested that, although sometimes he did disclose, at other times he was just waiting to be asked. Ralph, like Margaret, mentioned previously, appeared to be limited both by wishing to be selective and not knowing how to broach the subject. Ralph:

- ❑ reported that his GP had his literacy needs on the computer and so explained things to him
- ❑ advocated having low literacy noted on medical notes, acknowledging that this should be an individual choice
- ❑ reported that learning had increased his confidence to be able to say that he had dyslexia but that he sometimes doesn’t say anything
- ❑ perceived that staff may respond to disclosure in a way that stigmatised him
- ❑ declared that he finds it hard to tell people but doesn’t mind them knowing

However, asking the question and getting a response would only address the issue of disclosure. Participants who claimed to be open about their low literacy still found situations where they had to carry out literacy activities stressful. Yvonne reported being both open at work about any difficulties she might face and having an understanding manager. However, she wanted to be able to perform tasks which she then struggled with:

*“When I was at [Workplace 1] and they said, ‘Well, we’ll take you off the tills if you want.’ I says, ‘Well, I wanted to try’ but I was too slow at them so I had to get took off them, just go back to the general cleaning work and everything. .... they’ve put us into [Workplace 2] now which is much easier because I was stressed at [Workplace 1] as well. It’s easier for us.” (Yvonne, line 85)*

Being open about low literacy does not in itself necessarily get round all the problems and, in particular, for the Concealers, who are unlikely to respond to even the most direct offers of help, a universal approach that did not involve disclosure is the only potential solution. This was mentioned by several people and was viewed as appropriate specifically to avoid people being singled out and identified as being different. However, when Barbara, who was categorised as a Concealer, reported the helpful experience she had had when a surgeon had given her an audiotape explaining what she needed to know, she indicated that she did not know if he did it for everybody. This suggested that there may be situations where those receiving a particular service response would be unaware whether this was universal practice.

Ralph advocated a universal approach in providing explanatory pictures on health information leaflets, with healthcare staff ensuring that people could follow them and further advocated a universal approach:

*“ .... not just the nurses but the doctors as well and stuff like that explaining that you need to take these pills at these time and in the leaflet that she points to the right thing that says you know just more explaining and any questions that you want to ask*

*gives more understanding. It's more verbal than it is written if you know what I mean..... I think it should be done with everybody even though people are... most people can read and write and stuff but if you was to put it across the board, it would look less of a stigma. If everybody's got it rather than if nobody's got it.” (Line 297)*

While the suggestions thus put forward and discussed warrant consideration, any service response also needs to take into account the existing barriers for those with low literacy.

### **6.6.5 Barriers within the NHS**

Overall, it would appear that lack of awareness or sensitivity to the possibility of low literacy skills among healthcare staff contribute to a social context where literacy skills are both assumed and required.

*“I think that [healthcare staff] think everybody could read.” (Katy, line 420)*

The lack of sensitivity to varying levels of literacy; the reliance on written information, both in patient information resources and in hospital signage and directions; communication difficulties between patients and healthcare staff; and the reported complex language used in clinical consultations all constitute a range of institutional barriers to engagement for people with low literacy.

It appears that people with low literacy suffer discrimination in terms of access to healthcare services and support with self-management of health conditions because of these institutional barriers within the health service. As reported by participants, anticipation of stigmatisation and discrimination, which had been learned from an early age because of their experiences in a different social context i.e. the education system, prevented them from overcoming these barriers. It also potentially hampers service responses to facilitate the disclosure of low literacy through its strong influence on disclosure management. The universal approach to removing the barriers while also avoiding the need for patients to

disclose low literacy, as suggested by participants in this study would appear to be the most promising way forward to improve the experiences and clinical benefit of those with low literacy. This is explored further in Chapter 7.

## ***6.7 Conclusion to this chapter***

In answer to the three main research questions, low literacy appears to have an impact on people's health, either directly, indirectly or both. Some health service communications, particularly letters and information leaflets, are reported to be partly or wholly inaccessible to people with low literacy, suggesting that these are service resources that are not fulfilling their intended purpose. This has serious negative implications for people's use of health services and contributions to their own care (for example with people missing important appointments or not understanding how to use their medicines safely). The strategies that some people with low literacy use to help them work around the problems these difficulties create (for example, sharing information with others who can read it to them) may compromise their confidentiality or create patient safety issues. Health services may not adequately address the needs of those with low literacy and this, along with patients' coping strategies, may jeopardise engagement with healthcare staff and associated clinical benefit.

Many of the issues identified here are modifiable and several potential courses of action for healthcare providers were suggested and discussed. From these findings, it would appear that a more literacy-sensitive health service is likely to improve engagement and enable self-care activity in those with low literacy. The issue of stigma is clearly an important one and participant accounts suggest that it may be central to the decisions made around disclosure management; and to many aspects of mental wellbeing in people with low literacy.

## **Chapter 7. Discussion of findings and the way forward: Towards a literacy sensitive health service**

### ***7.1 Chapter overview***

This chapter begins with a summary of the process and findings of the research, describing the three stages consisting of the introduction to the topic; the systematic review of the evidence in relation to the hidden population, and the primary research. This qualitative study conducted as the primary research is among the first to have helped explain the findings of previous mainly quantitative studies in the existing literature. It has helped identify pathways to poor health as described in the first-hand accounts of those with low literacy along with suggestions for service solutions to the issues raised. The strengths and limitations of the study are presented and discussed.

Key issues which emerged from the findings are highlighted and discussed in the context of relevant bodies of knowledge. The findings place a new emphasis on health literacy, in highlighting the importance of aspects that are included in many definitions of health literacy but not in its measurement. The influence of low literacy on mental health is then discussed; this is followed by a focus on low literacy as a stigmatising condition, demonstrating that the primary research generated data related to stigma that were similar to what has been reported in relation to other stigmatising conditions. The study has made an original contribution to the body of stigma research, which has largely neglected low literacy. Low literacy is discussed and experiences of low literacy are considered in the context of first, the Social Model of Disability and second, the Capabilities Approach.

The findings are then considered in relation to national health policy, focusing particularly on the health inequalities agenda, single equality schemes and the principles of co-production and patients as partners. While the population with low literacy fits the profile of the

population groups that have been given a particular focus in developing the national equality schemes within the NHS, those with low literacy are less visible, both in practical and strategic terms than members of these other groups. The chapter concludes that the findings from this study can inform work to raise awareness of the existence and nature of this population and to develop initiatives which address their needs and concerns in order to improve their health, healthcare and self-care experiences.

*“I’m Charles Baker Harris,’ he said. ‘I can read.’*

*‘So what?’ I said.*

*‘I just thought you’d like to know I can read. You got anything needs readin’ I can do it ...’*

*‘How old are you?’ asked Jem, ‘four and a half?’*

*‘Goin’ on seven.’*

*‘Shoot, no wonder, then,’ said Jem, jerking his thumb at me. ‘Scout yonder’s been readin’ ever since she was born and she ain’t even started to school yet..’”*

Harper Lee<sup>190</sup>



## ***7.2 Introduction and summary of the study approach***

This study set out to investigate the ways that low literacy can impact on people's health and healthcare and self-care experiences. It was conducted in three stages and there follows a brief description of each stage prior to discussion of the findings and key issues raised.

Stage one highlighted that low literacy, perhaps more readily associated with developing countries, is a continuing problem in the developed world. The evolution of the concept of literacy was demonstrated, with a particular focus on health literacy, emphasising that functional and health literacy often overlap, not least because of the measures used to assess health literacy. The social practice view of literacy was introduced and highlighted as a useful model to guide the recommendations of the primary research. A broad literature review revealed that low functional or health literacy was associated with poorer health, healthcare experiences and self-management of conditions. However, many of the studies included populations with literacy problems that were likely to be evident to healthcare staff, such as people whose first language was not the dominant language of their resident country, or older people with cognitive impairment. This led to the introduction of the idea of a hidden population of people with low literacy whose difficulties may not be obvious to healthcare staff and others. This hidden population was the population of interest for the next stage of the study.

Stage two consisted of a systematic review of the literature to establish whether the previously reported associations between low literacy and poor health applied to the population which, for the purpose of the review, was considered to be people of working age whose first language was the dominant language of their country and had no obvious literacy difficulties.

The systematic review provided evidence of associations between lower functional or health literacy and poorer adherence to recommended/prescribed healthcare interventions; and

between lower functional or health literacy and poorer health that were broadly similar for the hidden population of people with lower literacy as for people who may have language and/or obvious cognitive/communicative impairments in addition to literacy difficulties. However, studies were mainly cross-sectional and did not explore causal associations, so that a number of important questions remained unanswered. The review concluded that further research was necessary to be able to understand the difficulties faced by people within this hidden population in accessing healthcare and in self-care activities and to identify the mediators and moderators in the relationship. This led to the primary research study which set out to explore the relevant difficulties that may be faced by people with low literacy.

A cross-sectional qualitative study, using individual face-to-face in-depth interviews and focus groups, was carried out as the third stage of this research. The aims of the primary research were to understand what pathways there may be between low literacy and poor health and to help identify ways that the health service may address issues raised.

The findings confirmed the existence of a hidden population of people whose low literacy may be neither obvious to, nor readily identifiable by, healthcare staff and others. Participants' accounts demonstrated that low literacy can impact on health through: impeding access to and engagement with health services; threatening the integrity of clinical consultations; and hampering self-care behaviours as well as negatively affecting participants' social and mental wellbeing. Participants' mental wellbeing was also affected by the stigma associated with low literacy. The influence of stigma on avoiding disclosure of low literacy also reportedly had an impact on participants' relationships with healthcare staff and their engagement with services. This emphasised the importance of aspects of health literacy which went beyond those related to written information but which nevertheless were associated with low literacy. Non-disclosure of low literacy to healthcare staff and lack of recognition of potential problems among service providers in general may exacerbate the issues raised.

A range of potential solutions to the issues raised was offered and discussed. These have helped to inform a proposed way forward for health services, discussed later in this chapter.

### ***7.3 Reflections on the study***

Existing studies in a considerable body of research literature investigating the associations between low literacy and poor health were mainly cross-sectional and quantitative. Potential pathways in the relationships had not been examined in any detail although some assumptions had been made and several authors had postulated what pathways may exist. This study set out to explore these pathways. The methods of achieving this had both strengths and limitations and these are discussed below along with my personal reflections on the study process.

#### ***7.3.1 Strengths of the study methods***

The study had four main strengths. These were: the sample achieved through the employment of a purposive sampling strategy; one-to one semi-structured interviewing which achieved the generation of data that would not have been captured by structured methods; focus groups which helped confirm the interpretation of the findings and allowed further discussion of potential solutions; and the personal experience I brought to the process.

In order to identify the range of beliefs, experiences and practices within the population of interest, a purposive sampling strategy was employed and this resulted in the recruitment of a diverse sample of participants with low literacy. The resulting participant sample covered both genders, a wide age range and various stages of literacy learning. It included people with multiple and enduring health problems as well as some who had enjoyed good health and whose contact with health services and requirements for self-care had been for minor illnesses only. This allowed for the exploration of a range of experiences of health and healthcare, taking into account factors such as age and gender that are known to impact on health. Recruiting learners at different stages of literacy learning had the advantage of

participants being able to reflect on changes over time and to consider their past experiences with hindsight. They were also able to talk about issues relating to their low literacy that they did not recognise until they acquired a new perspective on it.

The choice of in-depth interviewing as a method was made because of ontological and epistemological beliefs that social reality for the group of interest was both meaningful and could be constructed from the accounts of those concerned. Acknowledging that these experiences could only be known through the first-hand accounts of participants, the use of a flexible topic guide allowed the gathering of a rich data set which would not have been achieved through a structured questionnaire or a scripted interview. Neither would these more structured methods have allowed for the flexibility to modify the topics of interest, such as the changes that were made to the topic guide when the role of people's early experiences and the influence they had on their social interactions in adulthood emerged. Individual in-depth interviewing also allowed for customisation of the data generation at the time of interaction in two ways: firstly by allowing the participant to focus on and emphasise areas that were of particular concern to them; and secondly, allowing me to ask appropriate and relevant questions as the need arose. An example of the latter was that some of the participants had difficulties with more abstract questions. For example, they would reply to questions in terms of their own experiences but would struggle to speculate about what they might do in an imagined scenario or to express a view about the wider context of any issues raised, such as what it might mean for the health service.

To complement the individual interviews, focus group interviews were used as a way of checking and confirming my interpretation of the findings. These groups included both new participants and previous interviewees. As such, the groups provided: a forum to discuss what had already been raised; an opportunity to consider the range of options offered as service solutions; and a chance to introduce any new issues or potential solutions.

These interactions allowed me to explore the relevant issues through the experiences of those with low literacy, although it has been postulated that many social scientists who do not belong to stigmatised groups, and who study stigma do so from the vantage point of theories that are uninformed by the lived experience of the people they study.<sup>177, 191</sup> The result is declared to be a misunderstanding of the experience of the people who are stigmatised and the perpetuation of unsubstantiated assumptions.<sup>184</sup>

While belonging to the stigmatised group in question may bring epistemological privilege,<sup>152</sup> I would argue that not belonging to the stigmatised group had potential advantages. I was able to listen, document and analyse the data without referring to personal experiences of particular issues. As expressed in Chapter 3 in describing the assumptions I had made, I did anticipate that participants would feel that their low literacy was a problem in itself. However, my awareness that I was making such an assumption along with the method of data generation, discussed above, meant that it did not intrude on my questioning. Further, the staged analysis revealed a different viewpoint on the part of participants early on in the study process.

As well as making and maintaining unsubstantiated assumptions, other disadvantages of being outside of the stigmatised group of interest have been proposed. Fine and Asch suggested five assumptions made by social scientists who study but do not belong to groups experiencing disability:

- ❑ That disability is located solely in biology
- ❑ That the problems of the disabled are due to disability-produced impairment
- ❑ That the disabled person is a victim
- ❑ That disability is central to the disabled person's self-concept, self-definition, social comparisons and reference groups
- ❑ That having a disability is synonymous with needing help and social support<sup>192</sup>

Having worked for many years in Public Health, with a particular focus on health inequalities, I was fully aware of the stereotypes often attached to individuals whose personal circumstances led to their being categorised as 'deprived' or 'disadvantaged,' both suggesting and often encouraging stigmatisation. My experience, which had included contact with many such individuals led me away from such stereotyping or expectations likely to foster a patronising and unequal relationship between interviewer and participant. While focusing on the issue of low literacy and its role in experiences related to health had the potential to automatically locate it as a central issue in participants' lives, I took pains to avoid promoting this view in my questioning. The suggestions from the findings that for many participants it did appear to be an influence on their self-concepts and social relationships emerged from participants' own emphasis on the stigma and fear of stigma. The findings of the study were thus generated in a way that allowed participants to focus on experiences and issues that were salient to them. However, the findings also need to be interpreted in the context of some limitations.

### ***7.3.2 Limitations of the study methods***

The study had potential limitations in three main areas. These were: the recruitment of participants was limited to people who had recognised and sought help for their low literacy; a participant sample recruited on the basis of their literacy rather than health conditions, so that people with particular health conditions may have been excluded; and the possibility that some of the issues raised may not be unique to people with low literacy.

Participants had defined themselves as having difficulties with literacy through their attendance at the Adult Learning Centre. The recruitment of participants via adult learning classes may have excluded people who had not recognised or sought help for their low literacy. However, it would have been difficult to identify members of this hidden population in an ethically acceptable manner for research purposes only. The participants in this study *had* sought help but had previously or still experienced similar problems to those

experienced by members of the still hidden population. As mentioned above, the inclusion of participants who could reflect on past experience with hindsight and note changes that they may associate with learning was a strength of the study.

The reported experiences of participants in this study are not representative of all people with dyslexia and neither do they claim to be. In educational terms, there are many adults with dyslexia who have achieved success and entered professional careers. Robert Frank is a notable example of this. At the time of publication of his book in his book *'The Secret Life of the Dyslexic Child'*,<sup>193</sup> he had gained a PhD and was working as an educational psychologist, a family therapist and assistant professor of psychology. Participants were recruited because of their continuing need for support with their low literacy. These included people who had been diagnosed with dyslexia in childhood and had been supported through school but had not reached a level which they considered to be adequate for their requirements and as such, engaged with adult learning.

As described in Chapter 3, the decision not to employ recruitment criteria regarding clinical illness or multiple contact with services was based on two reasons. Firstly, most people have contact with some form of health service through their GP or pharmacist for minor conditions or over-the-counter medication. Secondly, people may not wish to disclose medical problems at the time of recruitment. The method of recruitment meant that tutors and possibly others in the literacy class would be made aware of their condition or at least that they had a condition through the learners' consent to participate in the study. It became clear during the interviews that participants may not have defined themselves as having a medical condition. Some participants replied to questions about attending the hospital by saying that they did not have any problems but during the course of the interview conversation they remembered one or more clinical appointments that they had attended.

In the interpretation of the findings, it may be that some of the issues raised by participants in this study are not issues for people with low literacy alone. Anyone may be distressed or

worried when they attend a clinical consultation and this may reduce their ability to take things in or to communicate adequately at the time of the consultation. Nevertheless, those who have low literacy skills will be compromised in any case and the findings highlighted issues which went far beyond individual literacy or communication skills.

#### ***7.4 Pathways between low literacy and poor health***

The primary research in this thesis set out to explore plausible pathways in the associations between low literacy and poor health that were established and described through the background and systematic reviews of the literature. The qualitative evidence presented within this thesis may help explain ways in which health outcomes are linked to low literacy, supporting and extending the findings in the existing body of research, most of which is cross-sectional and quantitative. This includes studies that demonstrate associations between low literacy and poorer health outcomes;<sup>71</sup> poorer management of health conditions;<sup>43, 88, 89, 98, 101</sup> less appropriate uptake of services;<sup>44, 87, 127</sup> and poorer health and function.<sup>9, 22, 90</sup> Many of the existing findings had a particular focus on issues related to healthcare services, which also featured strongly in the present study.

The findings of this primary research suggested low literacy can impact on health through: impeding access to and engagement with health services; threatening the integrity of clinical consultations; and hampering self-care behaviours as well as the direct (associated with low literacy itself) and indirect (through stigmatisation) impacts on social and mental wellbeing. These first three areas can be aligned with the domains suggested by Paasche-Orlow and Wolf in their conceptual model of the causal pathways between limited health literacy and poorer health outcomes.<sup>93</sup> They also offered three domains: access and utilisation of healthcare; patient and provider interaction; and self-care. Within each of these postulated domains, Paasche-Orlow and Wolf identified patient factors and factors external to the patient, drawn from existing published empirical research, which as already mentioned, consists of mainly cross-sectional quantitative studies.<sup>93</sup> Many of the factors suggested by



them are substantiated by the present findings, which are drawn from first hand participant accounts. The qualitative nature of the current study, however, provided greater insight to the reasons why particular factors linked to poorer health.

#### ***7.4.1 Impeding access to and engagement with health services***

Within one of the domains suggested as a causal pathway (Access and Utilisation of Health Services), Paasche-Orlow and Wolf listed patient factors of navigation skills; self-efficacy; and perceived barriers as links between limited health literacy and health outcomes alongside system factors of complexity; acute care orientation; and operating a tiered delivery model.<sup>93</sup> These system factors referred to the US systems of healthcare delivery, which are more complex than the NHS in Scotland. However, it could be argued that a service can appear complex to those who have difficulty understanding it and there was some evidence in the present study that participants had some misconceptions of how parts of the health service operate.

The current findings that participants reported difficulties with making their way around the hospital environment and with menus and notices for inpatients echoed the findings of Brez and Taylor,<sup>132</sup> who explored the healthcare experiences of a small sample of people with low literacy who had been hospital inpatients. The associated fear and worry over what was expected of them as inpatients were common to both studies.<sup>132</sup>

Memorising instructions rather than referring to written texts has been acknowledged elsewhere.<sup>194</sup> The reported use of memory supports my assessment of one study that was included in the systematic review, that memorising appointment times for their children may have been the reason that parents with low health literacy were reported as being more likely than those with adequate health literacy to know the date and time of their child's next well child appointment.<sup>126</sup>

The fear of actually or potentially having to engage in literacy activities during contact with health services came over very strongly in the present study and this constituted a barrier to full engagement for many participants. This may provide some insight into the excessive emotional responses reported in two studies included in the systematic review, one in a sample of women requiring colposcopy<sup>128</sup> and another among people living with HIV/AIDS.<sup>143</sup> The distress associated with treatment in these studies may be linked to the anticipation of accessing and engaging with healthcare services and staff to gain treatment and the fear of associated literacy requirements or disclosure.

Difficulties with written communication were an important issue for participants. Some health service communications, particularly letters and information leaflets, are reported to be partly or wholly inaccessible to people with literacy difficulties. This has serious negative implications for people's use of health services and contributions to their own care. As indicated by some participants, people may arrive for clinical appointments unprepared, both in terms of not bringing along necessary clinical samples or information and in having a poor understanding of clinical procedures they have to undergo. There are implications for the patients' experience of the clinical encounter which may help explain lack of engagement or failure to attend appointments or to follow instructions. These behaviours may be incorrectly attributed to low motivation or lack of interest by healthcare staff.<sup>116</sup> From a health service perspective, patients missing appointments due to their being unable to understand the appointment letters may be a major factor in contributing to the rates of patients who do not attend (DNA) outpatient clinics. Attendance at clinical appointments, however, did not always appear to be of optimal benefit.

#### ***7.4.2 Threatening the integrity of clinical consultations***

The suggestion from participant accounts that low literacy can impact on health through threatening the integrity of clinical consultations could well have been categorised in the Patient Provider Interaction domain offered within the Paasche-Orlow and Wolf model.<sup>93</sup>

However, the findings of the present study provide insights into issues associated with patient provider interactions far beyond those postulated in the conceptual model.<sup>93</sup> Participants in the present study described situations that demonstrated that it was mainly the relationships between themselves and healthcare staff that were affected by their low literacy and these were most likely to influence the process (and potentially the outcome) of a clinical encounter.

The influence of anticipated reactions of healthcare staff on the disclosure management strategies of those with low literacy was also highlighted in the Brez and Taylor paper.<sup>132</sup> Katz et al. found that patients with low literacy asked less questions in encounters with healthcare staff<sup>195</sup> and this is borne out by the findings of the present study, particularly in the accounts of participants who reported that they did not ask questions or ask for help because they viewed that as disclosure of their low literacy. However, Katz et al. also reported that those with low literacy were more likely to ask for things to be repeated.<sup>195</sup> This would potentially constitute asking for help according to the accounts of the present study's participants, so the two studies showed limited agreement.

The effects of low literacy and disclosure management featured heavily in several aspects of relationships with healthcare staff in the present study. Those associated with stigma and mental wellbeing are discussed later in this chapter under the relevant sections. The associated reduced engagement with healthcare professionals is likely to compound the difficulties already faced in engaging in relevant literacy activities and in particular, to significantly reduce patients' participation in decision making, factors postulated to be on the causal pathway and listed under the Patient Provider Domain of the Paasche-Orlow and Wolf conceptual model.<sup>93</sup>

Other factors under this domain offered by Paasche-Orlow and Wolf were knowledge; and beliefs.<sup>93</sup> Their conceptual model has been further developed by others, most notably in a later paper with an authorship which included Wolf.<sup>151</sup> In this later paper, which drew out

motivational and volitional determinants from social cognition models, knowledge and beliefs featured prominently. These included the ability of people with low literacy to obtain knowledge. Again the model was based on evidence from a review of the mainly cross-sectional, quantitative body of literature.<sup>151</sup> The findings of the present study raised the notion that patients' ability to obtain knowledge was adversely affected by both their low literacy and an associated disinclination to ask questions of healthcare providers. This had not been emphasised in the existing literature.

Paasche-Orlow and Wolf cited communication skills; teaching ability; and time as potential pathways in the relationship between low literacy and health.<sup>93</sup> Use of language affects both communication and teaching ability of professionals and other studies have reported difficulties for patients with low literacy associated with doctors' use of medical jargon during clinical consultations, for example, when making recommendations, providing health education, delivering test results and, to a lesser extent, when assessing symptoms.<sup>196</sup>

The belief that doctors were aware that patients did not understand what they were talking about and that they may communicate in this way intentionally was one of the main features of participants' stereotyping of healthcare staff, particularly doctors, in the present study. This belief reflects the findings of a study which examined the use of everyday language and medical language use of healthcare providers in their contact with patients in a hospital setting.<sup>197</sup> Doctors in particular were reported by patients as using medical language rather than the everyday language of the patient in their clinical encounters. The doctors themselves perceived that, although they did use medical language, they converged to the everyday language of the patient.<sup>197</sup>

Other authors have reported that patients with low health literacy were more likely to rate provider-patient communication in healthcare settings to be of poorer quality.<sup>198, 199</sup> Time also featured in participants' expressed opinions of clinical encounters. Some held the view that

doctors chose not take the time necessary to explain things, while others described time constraints on the length of appointments.

The threat to the integrity of clinical consultation is potentially further exacerbated by whether healthcare staff perceive a need for explanations and communication in everyday language or other relevant support. It would appear both from the literature and from the findings of the present study that there is low awareness among healthcare professionals of patients' low literacy. However, these may be sustained by patient factors, namely the coping strategies of those with low literacy. Patient strategies such as feigning understanding can imply competence in managing their health and prevent healthcare staff from discerning any problems. Again comparing this with conceptual models, patient centred care has been included as a factor in the postulated causal pathway. I would argue that patient centred care should include sensitivity to patient need and the provision of support to ensure that patients are equipped to perform self-management of health conditions.

#### ***7.4.3 Hampering self-care behaviours***

Findings from the present study suggested that self-care was compromised by factors associated with participants' low literacy. While there are many published studies linking low literacy with poorer management of health conditions,<sup>43, 88, 89, 98, 101</sup> the present study is among the first to offer potential explanations given by people with low literacy themselves.

Self-care was also designated as a domain in conceptual models of causal pathways<sup>93, 151</sup> encompassing patient factors that included motivation, which was examined in more depth in the later paper;<sup>151</sup> problem-solving; self-efficacy; and knowledge/skills. Participants' accounts suggested that they did have some relevant difficulties and their reliance on others appeared to have both advantages and disadvantages. Reduced ability to obtain knowledge (and associated skills), through less than adequate engagement in clinical encounters and subsequent missed opportunities for support, potentially contributed to compromising self-

care activities. Motivation was not raised, discussed or assessed in the current participant interviews.

Participants in the present study also described circumstances that suggested that low literacy may lead to low uptake of services designed to support self-management of health conditions, for example, support groups. The findings of this study highlighted two issues. Firstly, that people may struggle with the written information promoting and inviting them to participate in education and support type sessions relating to their long term condition. Secondly, the group setting favoured by many of the self-care support initiatives on offer may represent a typical situation that the person with low literacy would try to avoid. Several participants reported finding group situations particularly threatening in terms of fear of the need to participate in literacy activities. Bert's description of standing near the door in a group situation and his dread of being asked to read something illustrated this well.

Provider factors indicated in the conceptual models as potentially being on the causal pathway were support technologies; mass media; health education; and resources.<sup>93</sup> These were mentioned in the present study mainly in relation to suggested service solutions. In particular, support technologies were discussed and put forward as potential sources of help for those with low literacy.

Many of the factors identified in this study can be aligned with the pathways postulated by others in terms of the domains and issues within these.<sup>93, 151</sup> However, in addition, this study has identified that living with low literacy in itself can have an impact on the mental wellbeing of the person concerned. While the role of stigma and shame are acknowledged in the literature<sup>114</sup> and included in the conceptual models<sup>93</sup> participant accounts in the present study have further highlighted that stigma is a central feature in the lives, literacy-related social practices and other social interactions of those with low literacy. Stigma is one of the key issues considered in the next section in relation to the relevant existing research.

#### **7.4.4 Low literacy and mental health and wellbeing**

The perceived negative impact of low literacy on participants' mental health and wellbeing, as declared in their accounts, is consistent with other findings. Weiss et al reported the likelihood of lower psychosocial scores among those with low literacy.<sup>91</sup> The present study extends and supports these findings by highlighting ways in which low literacy can impact on mental wellbeing. Weiss et al. suggested that their study may have underestimated the prevalence of low psychosocial wellbeing in the wider population with low literacy because their sample population was drawn from people who had engaged in literacy learning.<sup>91</sup> The present study provides empirical support for their suggestion, with the reported improvements in mental wellbeing that participants attributed to their engagement in learning and this is discussed later.

Mental health, by definition, includes social as well as individual features, social engagement as well as individual capability. It was described by WHO as *"not just the absence of mental disorder. It is defined as a state of mental well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to her or his community."*<sup>200</sup> The Mental Health Foundation, in a similar vein, described good mental health as being able to *"make the most of your potential, cope with life and play a full part in your family, workplace, community and among friends."*<sup>201</sup>

The participants in the present research reported varying degrees of achievement of these aspects and identified areas where they had been less able to function adequately or fulfil their potential. In particular, for various reasons, participants did not perceive that they had reached their potential when their education had suffered because of lack of either support itself or recognition that support was needed. Their contribution and ability to *"play a full part"* in social interactions, in education, in health and in work contexts appeared, in many cases, to be compromised by the low literacy itself, as well as the associated shame and stigma.

Participant accounts highlighted that the majority had had, for various reasons, reduced opportunities for education or suboptimal education experience or both. Individuals also reported experiencing stress at work because of their low literacy and expressed feelings of disengagement and isolation in a range of social situations. All of these, namely, low levels of education; stressful work conditions; and social exclusion have been described by the WHO as factors that contribute to poor mental health.<sup>202</sup>

Poor mental health is also associated with neurotic or psychotic symptoms. Neurotic symptoms have been described as “*severe forms of ‘normal’ emotional experiences, such as depression, anxiety or panic.*”<sup>201</sup> Viewing dyslexia through a medical (biological) lens, the neurological characteristics are not directly associated with psychotic symptoms. However, psychological and social factors which impact on mental health, such as low self-esteem and felt and enacted stigma have been reported in this study and neurotic symptoms, perceived by participants to be linked to literacy problems, were reported frequently.

Participants in the primary research reported that improving their literacy skills improved aspects of their mental health, emphasising the role of literacy in mental health and wellbeing.

#### ***7.4.5 Literacy learning and improved mental wellbeing***

Literacy learning was reported to have had positive effects on the mental wellbeing of participants. Participants described social situations where they felt they were more able and more confident to participate since improving their literacy through learning. Goffman proposed that when a stigmatising condition is repaired, the person becomes someone who has corrected a particular blemish rather than one who acquires fully normal status.<sup>175</sup> The more hidden nature of low literacy may help avoid this continued labelling and this was substantiated to some degree by the participant accounts.



The findings of the current study suggested, however, that seeking help to improve low literacy is not straightforward, but associated with a complex range of attitudes, behaviours and not least, the need to disclose and face the issue. It is also the case that substantial changes in literacy skills tend to take a long period of time and high level functioning may not be achieved at all. Further, there should not be an assumption that advanced literacy skills are the aim. The social practice approach to literacy emphasises customised learning for adults so that they are able to function in social contexts according to their particular requirements.

Many of the participants indicated that their initial interview at the Adult Learning Centre to discuss their learning requirements had revealed some new perspectives for them. This was one of the ways in which self-esteem and mental wellbeing appeared to have improved, through participants' creation of 'counterstories.' According to Nelson, "*a counterstory is a story that resists an oppressive identity and attempts to replace it with one that commands respect.*"<sup>203</sup> Olive and Margaret created 'counterstories' of their earlier life, expressing that they had a better understanding of the reasons for their low literacy and a realisation that they weren't 'stupid' or 'thick.' This was suggested in the accounts of others, who reported feeling better or having a better understanding of their difficulties after their initial interview or after a diagnosis of dyslexia.

In spite of reported changes to the self-concepts of many participants, feelings of stigma in social situations were still expressed. For example, Margaret declared that she needed to be able to trust people not to think she was stupid before she would disclose her low literacy. This suggests that without a change to the way that others view those with low literacy, counterstories do not remove the stigma. It is therefore important to also change the master narratives, which Nelson described as "*repositories of common norms.*" Master narratives, according to Nelson, are stories in particular cultures that serve as summaries of socially shared understandings.<sup>203</sup> The master narratives about low literacy may be difficult to change for a number of reasons, not least because of the lack of shared identity and

collective action of those concerned. Link and Phelan postulated that once differences are identified and labelled, they are typically taken for granted as being just the way things are<sup>184</sup> suggesting that beliefs about stigmatising conditions may be difficult to reverse.

Some efforts have been made to change master narratives, for example, the “See Me” campaign, a Scottish Government initiative to lessen the stigma of mental ill health. A change of master narrative which stigmatised a behaviour that was previously socially accepted, can be seen in the smoking ban in public places in Scotland which would appear to have stigmatised smokers somewhat. The findings of the current study have added to the body of knowledge within existing stigma research through providing insight into the relevant experiences of those with low literacy.

## ***7.5 Relating key issues in the findings to broader bodies of knowledge***

The overview of the findings above has highlighted how low literacy may impact on people’s health and self-care experiences and the implications for health services delivery, reiterating published evidence, and helping to support and explain the links postulated by others. Several other key issues emerged from the findings and these include stigma which appeared as a significant feature in the lives of participants and one which was associated with the links between low literacy and poor health discussed above. The effect on participants’ mental health and wellbeing of stigma associated with low literacy potentially compounds the impact of low literacy itself. In addition, the findings from this study have contributed to the body of stigma research, which, to date, has largely neglected low literacy as an issue.

### ***7.5.1 Stigma***

Stigma clearly played a major role in participants’ lives, in their disclosure management strategies and in their contact and relationships with healthcare staff. There follows an

examination of this in the context of stigma research. This begins with consideration of the case of low literacy and its associated stigmatisation.

#### **7.5.1.1 Low literacy as a stigmatising condition**

Low literacy would appear to be a particularly stigmatising condition and although the paper by Parikh et al. describing the shame and stigma<sup>114</sup> is much quoted in the literature focusing on health literacy, low literacy has not commonly featured in the body of stigma research. In this section, I explore potential reasons for such stigmatisation and compare low literacy with other stigmatising conditions.

In examining the social psychology of stigma in general, Heatherton et al. proposed that the predominant view of stigma researchers is that particular cultures and subcultures define which characteristics are stigmatising and which are not.<sup>204</sup> Link and Phelan also discussed the social selection process, suggesting that in the identification of differences that are deemed relevant and consequential, some are highly salient in certain social contexts, citing the examples of skin colour, IQ and sexual orientation.<sup>186</sup> Indeed, the social and cultural context of the stigmatisation of low literacy has been acknowledged:

*“...in countries where writing is all-pervasive and where a command of the written language is not only an everyday requirement but is, in its highest form, a sign of cultural and social distinction, a total lack of that ability or few or merely poor writing skills are bound, sooner or later, to debar people from all sorts of opportunities and may even make them feel deeply ashamed”<sup>2</sup>*

Literacy appears to have an association with a particular status, but also an expectation in certain cultures. When Charles Baker Harris, or Dill, as he is known in Harper Lee’s novel *‘To Kill A Mockingbird’*,<sup>190</sup> introduced himself to the Finch children, he pointed out his ability to read as an indication of his social status or ‘social distinction’ as described by Velis, above.<sup>2</sup> The response Dill received from Jem Finch suggested that being able to read was no more than expected and a skill that could be achieved very early in life. The idea of

literacy being symbolic of social worth was reported by Bialostok, who explored the normative culture of literacy among middle class parents. Bialostok's qualitative study suggested that for those parents, not only was reading books associated with moral worth, but teaching children to read had an accompanying primary goal of reshaping the moral character of families, particularly those from minority groups.<sup>113</sup>

In an organisation such as the NHS, most of the clinical encounters are with educated professionals, who rely heavily on written information. There is an implicit expectation that patients should be able to engage with this aspect of service delivery and thus, institutional discrimination against those who may struggle to do so. Participant accounts revealed that in clinical encounters, where the literacy level required to engage in interactions was set by those healthcare professionals they often felt excluded and appeared to be unable to alter the situation by expressing their lack of understanding or asking for help.

While the social context of healthcare may typically have involved encounters with people who were viewed as potential stigmatisers by participants in the present study, their accounts also suggested they did not perceive the stigmatisers to be exclusively professionals. This appeared to be the case for those who reported that they did not wish their friends, and in some cases, members of their own families to know about their low literacy; where partners had not been told; in examples such as that given by Megan, who described her partner denigrating her for her low literacy while denying his own difficulties; and the many who reported worry over whom they might encounter as peers at the Adult Learning Centre. The circumstances thus described question the idea that within society, the same person may be stigmatised in one context but not in another.<sup>204</sup> Indeed, it would appear from the participants' accounts that there are few social contexts in Scotland where low literacy is considered to be non-stigmatising for adults of working age who speak the dominant language of their country and have no obvious cognitive disabilities.

The fear of stigmatisation expressed by participants in their descriptions of going along to the Adult Learning Centre for the first time may be comparable to what has been proposed in relation to medical conditions, that is, that the fear of being labelled with a disease may lead to individuals avoiding treatment or if already labelled to distancing themselves from the treatment or be non compliant.<sup>186</sup> It may also help explain the low uptake of adult learning in the total population with low literacy, reflecting a preference to avoid joining or being identified as belonging to such a group. Literacy thus appears as a particularly stigmatising condition and although socially widespread, it is nevertheless culturally set.

In a country such as the UK, where education is freely available, compulsory and valued both in itself and as the pathway to employment and economic success, those with low literacy are likely to be stigmatised. Acknowledging the cultural context of this stigma and shame leads to the notion that an individual from a society with limited educational opportunities and where illiteracy is common would not be so stigmatised and may be more willing to admit a problem. This has been borne out, for example in one study which found that women from rural Mexico who had been denied an education expressed anger rather than shame about their reading problems.<sup>101</sup>

In the context of free and compulsory education, there may be a common belief that there is 'no excuse' for low literacy and a degree of blame may be attached to the individuals concerned. Similar to other stigmatising conditions then, low literacy may be viewed as having internal controllability, so that others may believe that the stigmatised person is responsible for the stigma. This view sometimes underpins justification of the stigma.<sup>205, 206</sup> Obesity is another example of such a condition, whereby overweight people may be believed to be responsible for their own weight, so there is a blame factor in their stigmatising condition.

In the present study, participants themselves appeared to have the view that they held a degree of responsibility or blame for their situation when they reported missing school or not

working hard at school and, although there were exceptions, notably Fraser, who felt he had been let down by his schooling, most did not view the education system as having any responsibility for their lack of achievement or low literacy. Some who had commented that their problem was not picked up by the school, qualified the statement with a reason why that had not happened and suggested that the school was not to blame, such as when Yvonne stated that 'they' were unable to detect literacy problems when she was at school, adding that she was useless and kept skiving off, perhaps laying more of the blame on herself. Again, for some, this balance shifted when they engaged with the Adult Learning Centre and reviewed their school experiences in a new light, at least partly attributing the problem differently. The evidence of self-blame perhaps confirms the feelings of felt stigma apparently experienced by participants.

The presence of a medical reason for a condition may remove the blame. For example, becoming HIV positive through a blood transfusion may be viewed as blameless compared with HIV positive status as a result of unprotected sexual activity or sharing of drug injecting needles. The implication that individuals have chosen certain behaviours is more likely to lead to stigmatisation of these individuals.<sup>207</sup> It would appear from this study that a formal 'diagnosis' of dyslexia was not necessarily regarded as providing a blameless explanation for low literacy. Although some participants said that they told others of their dyslexia as a way of explaining the reason for their low literacy skills, many reported that they still felt stigmatised because of it and participants, including those known to have dyslexia, often associated their low literacy with being considered to be stupid and continued to hide it.

It may also be reasonable to assume that the moral agency of someone who does not have adequate literacy would potentially be in doubt, as suggested by Goffman with regard to some stigmatising conditions.<sup>175</sup> Being judged and feeling that their ability to look after their children may be questioned, that is, their moral agency threatened, featured in the present study among young mothers, several of whom reported this to be a major consideration in deciding whether to disclose their low literacy or not. Indeed, their fears were often reported

as being central to their disclosure management strategies. Similarly, Brez and Taylor reported that the participants in their study stated that they felt fear that their role as a competent adult, parent or family provider would be challenged if their literacy problems were revealed.<sup>132</sup> Keeping their low literacy hidden was therefore important and participants in both studies reported having a degree of control over being identified and labelled. Other conditions, such as obesity, are immediately evident and do not lend themselves to the same possibilities for concealment.

For those with stigmatising conditions which are concealable, coping strategies involve making a decision about whether to disclose and potentially suffer stigma, or to attempt to conceal and 'pass for normal.' Joachim and Acorn presented a framework that described the relationship between stigma and the decision to disclose or hide a chronic condition based on its visibility or invisibility.<sup>181</sup> Low literacy, in its invisibility, would seem to afford considerable opportunity to avoid disclosure. As such, low literacy has some similarity to conditions such as HIV/AIDS and epilepsy, which are the subject of much of the research on stigma. These and other similar conditions can be hidden most of the time and the individuals concerned can 'pass as normal.' However, the ability to pass will often be dependent on the social context and in the case of literacy, on whether there is a requirement to participate in literacy activities in any particular situation.

Being confronted with an activity that requires them to use their literacy skills appears to be a great fear for those with low literacy and although there are similarities among different stigmatising conditions in the fear that the stigmatised person experiences, there may be differences in the amount of control people have over the likelihood of their fear becoming reality. For example, people with epilepsy may fear having a seizure in public,<sup>179</sup> and in comparing the two groups, it may be argued that those with low literacy have more control over their 'feared event.' Nevertheless, the anticipation of such an event would appear to be ever present according to the accounts of participants in the present study, and the degree of control dependent on the particular situation in which the person with low literacy finds

himself. For example, participant accounts suggested that, in healthcare consultations, control was retained by them as patients through disclosure management but there was still the element of the unknown. This featured particularly at hospital appointments and several participants reported the dread of finding themselves having to read or write something as part of the healthcare consultation process.

Acknowledging the particular features of literacy as a stigmatising condition, the control of relevant information appeared to be much greater in adulthood than was described in participants' childhood years when the stigma and separation had been established.

#### **7.5.1.2 The spoiled childhood**

Many participants had experienced labelling and separation from their peers in early childhood. Participants' descriptions of their childhood experiences: the feelings of not fitting in; of isolation; the fear of discovery; of being made fun of; and of being called stupid; all reflect the feelings of children with dyslexia that were depicted by Robert Frank.<sup>193</sup> Frank, whose dyslexia went undiagnosed until he was in graduate school, highlighted an event in adulthood when he was in a group of professionals who were required to read aloud from a pamphlet. He described being amazed to feel *"the same sense of fear pulsing through my body that I had felt as an 8-year-old child being asked to read aloud in class."*<sup>193</sup>

In school situations, where literacy problems are often more transparent, enacted stigma by both peers and teachers was presented as a prominent feature in the lives of many of the participants in the current study. The fear of discovery described by Frank<sup>193</sup> appeared to remain a fear for many. The role of teachers in stigmatising those with low literacy was highlighted in participants' accounts, such as in Margaret's declaration that her teachers' humiliation encouraged her peers to bully her. Bigler et al. postulated that a deciding factor in whether or not children acquire stereotypes about visibly different others is whether educators make those differences salient. Their study of elementary school children aged 6 - 9 showed that the functional use of two colours of t-shirts and shorts worn by the children,



that is, when the teacher drew attention to the different colours and categorised them accordingly, affected children's attitudes towards group members. The children were reported as showing bias in favour of their peers who wore the same colours.<sup>208</sup>

Low literacy was a salient feature in school for a number of other reasons. Many of the participants in the present study came from a generation when streaming according to ability was carried out in the school system, when children had to repeat a year if they did not reach an acceptable level of achievement and when the 11+ exam was taken in the last year of primary school to decide choice of secondary school. In these circumstances, low literacy was likely to be more visible at school and if it was also portrayed as stupidity by teachers, peers were likely to be influenced and to consider those concerned to be stupid.

The process of stigmatisation in participants' childhood years was not exclusive to school experiences but was seen in attitudes and behaviours of parents and other close family members. This substantiates the view that people learn to be discreditable from significant others,<sup>178, 180</sup> particularly parents.<sup>181</sup> Felt stigma would therefore appear to generate mainly from those who are most influential in people's lives. As well as describing examples of stigma coaching by their parents, participants reported experiencing stigmatisation and discrimination instead of support from the authority figures in their young lives, mainly teachers. This could also be considered as stigma coaching for later life and may help explain the low levels of disclosure to authority figures in the NHS, namely hospital consultants and other healthcare professionals because of anticipated stigmatisation and fear of repeating past negative experiences. Behaviours and feelings in adulthood were described as having been influenced by these childhood experiences.

#### ***7.5.1.3 Stigma strongly felt in adulthood***

The data gathered in this primary research demonstrated that stigma played a major role in participants' day to day lives in adulthood. It affected their health status, particularly in relation to their social and mental wellbeing. Stigma also had an impact on their engagement

with and relationships within healthcare services, and on their willingness to enlist help or ask for advice from healthcare professionals on the self-management of their health.

Felt stigma appeared to feature more strongly than enacted stigma in healthcare contexts and this is in agreement with what has been postulated in the literature.<sup>179, 180</sup> Few examples of stigmatisation by healthcare professionals appeared in the participant accounts but the anticipation of being stigmatised was a major issue and one frequently associated with non-disclosure of low literacy and limited engagement in clinical encounters. This balance between felt and enacted stigma was reported by Scambler and Hopkins, who found that people diagnosed with epilepsy perceived their epilepsy as a stigmatising condition but few could recall any actual instances of stigma or discrimination against them.<sup>180</sup> Similarly, Jacoby reported that people whose epilepsy was in remission continued to feel stigma.<sup>179</sup> However, Scambler and Hopkins also suggested that one effect of felt stigma was to reduce opportunities for enacted stigma, because it led to attempts to conceal the stigmatising condition whenever possible, in the hope of protection against potential discriminatory acts.<sup>180</sup>

For participants in the present study, stigmatisation and discriminatory acts had reportedly been experienced by them in earlier years, particularly at school, and their felt stigma and expectation of discrimination was often attributed to these previous experiences, which they sought to avoid repeating.

Covering and passing strategies employed in maintaining concealment of their low literacy were also reported as stressful and participant accounts suggested an ever present stigma potential, as described by Schneider and Conrad.<sup>178</sup> Stigma potential, which exists when the person is felt to be discreditable rather than actually discredited,<sup>178</sup> seemed to have a major influence on participants' interactions with healthcare staff. The commonly reported practice among participants of concealing their low literacy from healthcare staff was frequently associated with fear and worry that their low literacy would be discovered and they would

suffer the accompanying stigma. In relation to this, the idea put forward by Schneider and Conrad was that a discreditable attribute or performance becomes relevant to the individual only if that individual perceives it as discreditable regardless of whether or not such perceptions are actually applied by others to self or *“simply considered as a relevant object in the environment that must be taken into account.”*<sup>178</sup> This related well to the notion that felt stigma featured more strongly than enacted stigma in clinical encounters. The idea that most participants did not appear to consider the possibility that their low literacy would be regarded by healthcare staff as something to be taken into account was evidenced in two ways: firstly because of the reported anticipation of enacted stigma if they were to reveal their literacy difficulties; and secondly because of the responses received from participants when they were asked if they thought it mattered if healthcare staff knew about their low literacy. Some highlighted implications for patient safety if healthcare staff were unaware of their low literacy; and the importance of being able to understand conditions and how to deal with them was also raised. However, the majority did not offer the view that it could be an advantage for healthcare staff to know nor did they cite any perceived benefit to sharing the information. Some emphasised this by giving reasons for not letting doctors know, such as stating that it was none of their business or not knowing what they would suggest to deal with the ‘problem.’

It could be argued then, that in adulthood, clinical encounters were affected by participants’ felt stigma or stigma potential, substantiating Goffman’s proposal that the presence of a stigma would be expected to influence the perceptions and feelings of both individuals and the interpersonal behaviours as well.<sup>175</sup> In these cases, healthcare staff were not necessarily aware of the stigmatising condition but the stigma influenced the behaviour of participants almost as if they were. This was suggested by Harry, who claimed that the hospital consultant had considered him to be stupid even though he had not explicitly revealed his low literacy.

Pinel called the expectation of stereotyping '*stigma consciousness*' and developed a stigma consciousness questionnaire, validated by 5 of 6 studies presented in one paper, concluding that people high in stigma consciousness were more likely to perceive discrimination directed toward their group and toward them personally and were more likely to provide sound evidence for these perceptions.<sup>209</sup> Pinel also postulated that stigma consciousness may encourage continued stereotyping,<sup>209</sup> citing experiments which showed that cosmetically applied facial scars were reported to have influenced social interactions even when the scars had, in fact, been surreptitiously removed prior to the interaction.<sup>210</sup> While this particular paper focused on the behaviour of the individual, the situational influence on stigma consciousness was acknowledged. I would argue strongly that situationally induced stigma consciousness is a more prominent feature in the current study. Although the expectation of stereotyping influences the individual's behaviour, that expectation is itself influenced by the other participant(s) in any particular social interaction. Participants in the present study indicated that they attributed the differences in their disclosure behaviours among healthcare professionals to the expected reaction of the healthcare professionals in question. General practitioners, for example, were frequently more likely to be made aware of low literacy than hospital consultants, and this was often associated with the history and relationships, and the lower expectation of stigma or stereotyping the participant had of their GP.

People who have high stigma consciousness do not necessarily agree with the stereotypes related to their condition or believe that these stereotypes apply to them.<sup>209</sup> Stigma schematicity has been described as different from stigma consciousness in that people who are stigma schematic have internalised their beliefs associated with their stigma.<sup>209</sup> Thus, Pinel's introduction of the concept of stigma schematicity is helpful in illustrating the plight of those with low literacy and I propose that it brings together the idea of low literacy being a particularly stigmatising condition, discussed earlier, and the notion that once the cultural stereotype is in place it can affect labelled persons in important ways that do not involve

obvious forms of discriminatory behaviour on the part of others.<sup>184</sup> Some participants in the present study would appear to have internalised their beliefs about low literacy, for example, that their literacy was limited because they were stupid or did not work hard enough at school, particularly in their accounts of their experiences before they had accessed learning to improve their literacy. As mentioned earlier, this implied some blame on their part, supporting the idea of attributional justification of stigma which exists in particular cultures and sub-cultures. Other participants, sometimes adamantly, expressed the belief that they were not stupid, some more so in light of having reviewed the issue of their low literacy after engaging with the Adult Learning Centre. As Pinel pointed out, however, this belief could still be accompanied by high stigma consciousness<sup>209</sup> and this was demonstrated among several participants. Katy is an example of this, declaring that she wasn't stupid and could understand things if they were explained to her. Nevertheless, she concealed her low literacy because of the anticipation that healthcare staff would patronise her and talk to her as if she was three years old.

Farina et al. also postulated that a stigmatised individual's perceptions and actions toward another person in an interaction would be greatly influenced by his stigma, independent of the other person's behaviour. They further suggested that the person who was blemished may indeed contribute more to the difficulties in social relationships than the person with whom he interacts,<sup>211</sup> adding that if an individual believes he is perceived in an unfavourable way by another person, his behaviour in a subsequent interaction is affected independently of the other person's actions in the situation. They further offered the possibility that the social rejection which people who have stigmata fear and expect is, to some degree caused by themselves.<sup>211</sup> The result, they concluded may be strained and uncomfortable social interactions with potential stigmatisers; more constricted social networks; and low self-esteem.<sup>211</sup>

Although the study by Farina et al. dealt with a problem that their participants didn't actually have,<sup>211</sup> those in the current primary research offered descriptions of: feelings of low

confidence and self-esteem; constricted social interactions; and social restrictions, such as Harry who declared that he had no friends, and Carol whose low confidence was viewed by her as preventing her from day to day activities such as shopping or having lunch out unless she was accompanied by a trusted confidant. Many of these circumstances were described in the absence of reports of enacted stigma in adulthood.

Management of information has been described as critical in the lives of people with chronic illnesses and conditions and it has been proposed that individuals may be uncertain about disclosure, whether or not, to whom, and how much to disclose.<sup>181</sup> But while disclosure might reveal information that could discredit the individual, hiding the condition also has risks, including the threat of being found out. Either way, risks include being rejected and stigmatised; having difficulty handling the responses of others; and losing control.<sup>181</sup> It has also been suggested that people's efforts to cope with labels by educating or withdrawing from potentially stigmatising situations or by keeping information secret, can be harmful because the efforts often result in further social isolation and they reinforce patients' stigmatised self-concepts.<sup>212</sup>

Awareness of stigma potential or stigma consciousness among participants appeared to lead to the control of information about their low literacy through various disclosure management strategies and these appeared to be the central feature in reducing interaction and engagement in healthcare processes.

Several day to day scenarios which involved literacy activities and had the potential to elicit active management of information about their literacy featured in the interviews. In general, manual jobs may appear to be free of literacy activities but safety notices may need to be read and adhered to and there are social situations in the workplace where the person with low literacy may struggle or feel the need to pass as normal. For example, Bert reported pretending to read a newspaper at tea break because that was what everyone did. Other similar situations may arise where coping strategies may be required to avoid being

identified and labelled, such as the need to choose lunch from the menu in the staff canteen. Participants' descriptions of their fear of being uncovered and stigmatised are a reminder that passing is a stressful activity and that it does not always create a situation where the person with low literacy can feel confident that their passing is successful, has gone unnoticed or will not be discovered.

Management of information about low literacy may, of course, include disclosure as well as concealment even when the information is potentially discreditable. In a study of people with epilepsy, Schneider and Conrad reported that, except for those who adopted rigidly secretive strategies, most people usually or always told certain others of their epilepsy under certain circumstances.<sup>178</sup> In the present study, those participants whom I categorised as Concealers could be considered as having adopted 'rigidly secretive strategies' while the others, particularly the Limiters, reported stances similar to those in the findings of the epilepsy study, which elaborated by indicating that sometimes people concealed their epilepsy, sometimes they didn't and the same person could be open and closed during the same period in their lives. In the present study, being open and/or closed was associated with particular situations or social interactions and this was also recognised in the epilepsy study. Schneider and Conrad proposed that disclosure or non disclosure may have less to do with one's identity than with the more practical matter of preventing others from applying limiting and restrictive rules that disqualify one from normal social roles.<sup>178</sup>

Schneider and Conrad also made the point that hiding a particular stigmatising condition is sometimes described as being "*in the closet*" but that such terminology assumes that one can only be in or out and that being out must follow a period of being in. They considered such a view as much too simple, pointing out that both concealment and disclosure were quite complex, describing the closet of epilepsy as having a revolving door. I would strongly agree with this view since it featured heavily in the descriptions of disclosure management strategies of participants in the present study.

Katy portrayed the revolving door when she speculated that letting healthcare staff know about her dyslexia would involve having to say it over and over. I would liken this to when people who are gay ‘come out.’ Unless they are famous pop stars or actors, so that the revelation that they are gay is broadcast to the general public through various media, people tend to come out initially to those close to them and even becoming ‘openly gay’ involves telling people as each situation arises, with potentially varying reactions from the recipients of the information. Similarly with literacy, as well as the suggestion that repeated disclosure would be necessary in a healthcare context, participants’ accounts included a strong suggestion that even those who declared themselves to be open about their low literacy rarely revealed it to those with whom they had contact in relation to literacy activities. This was identified by participants as being linked to their awareness of their stigma potential and the anticipated reactions of others. Schneider and Conrad offered a quotation from a participant who stated: *“I have to trust someone a lot before I’ll tell them [about my epilepsy]”*<sup>178</sup> and this condition attached to disclosure is similar to those expressed by participants in the present study. Margaret, in particular, echoed this quotation verbatim.

Stigma, felt or enacted, and stigmatisation, potential or experienced, all appeared to feature strongly in the lives of those with low literacy. Evidence from the literature and the findings of this study suggest that stigma is likely to have an effect on the mental wellbeing of the individual concerned.

#### **7.5.1.4 Stigma and mental health and wellbeing**

As discussed earlier, participants perceived an effect on their mental health and wellbeing which they attributed to low literacy itself. Perhaps more significantly, the shame and stigma associated with low literacy appeared as a source of poor mental health and wellbeing as did the reported need for frequent disclosure management behaviours.

My earlier suggestion that people who had sought help with literacy may be more likely to reveal their difficulties to healthcare staff was not borne out by my primary research, since



most of the participants reported that they had not disclosed their low literacy to healthcare professionals with whom they had been in contact. This was still the case among those who had been attending adult learning for some time and reported improved confidence as a result, which they often described as being associated with an increased likelihood of asking questions. Few participants reported being any more likely to disclose their literacy needs to healthcare staff than they had been prior to attending the Adult Learning Centre, so that improved mental wellbeing did not necessarily impact on the issues associated with disclosure management. The impact of stigma on mental health and wellbeing was also evident in aspects of participant accounts which were not necessarily recognised or attributed as such.

Stigma has been described as a persistent predicament, along with the suggestion that although there is a general pattern of disadvantage connected to stigma, not everyone suffers the same outcome.<sup>184</sup> It has been argued that although those who possess a stigma may experience more stress because of it, this does not necessarily translate into poor mental health.<sup>213</sup>

Although the experience of being stigmatised may take a toll on self-esteem and other outcomes, many people with stigmatised attributes have high self-esteem, perform at high levels, are happy and appear to be quite resilient to their negative experiences<sup>204</sup> Positive effects of stigmatisation have also been postulated in the literature, such as the enhancement of self-esteem through the motivation of favourable intergroup comparisons; or the perception or achievement of positive group distinctiveness<sup>204, 214</sup> However, I would suggest that these are unlikely scenarios for people with low literacy, not least because of the hidden nature of their 'stigmatising condition' and the shame and fear associated with it. This was further supported by participants' accounts, which included the mention of stress in a negative way as well as depression and other responses, which highlight the potential mental health consequences of such stigma. The Health Education Authority defines mental health as: *"a positive sense of wellbeing and an underlying belief in our own and other's*

*dignity and worth.*<sup>215</sup> Feelings of low self-esteem and low worth were reported experiences throughout the lives of many participants, particularly in the early years when the labelling and stigmatisation were first experienced, as a result of which, strongly felt stigma and associated feelings of low worth were described as having been carried on into adulthood.

While participants did not all report negative effects on their mental wellbeing directly, the comparison of their claimed attitudes to disclosure with their reported disclosure management behaviours suggest that there may have been fairly comprehensive stigma consciousness across the participant sample.

Scambler and Hopkins proposed felt stigma and fear of enacted stigma to be typically associated with more personal anguish and unhappiness than enacted stigma itself. They described felt stigma as a source of unease, self-doubt and disruption in people's lives.<sup>180</sup> Similarly, Goffman postulated that the possession of a discreditable attribute weighs heavily and shamefully on one's own definition of self, whether or not others have the same knowledge.<sup>175</sup> This was reiterated by Heatherton et al. who suggested that those who perceive themselves to be members of a stigmatised group, whether it is obvious to those around them or not, often experience psychological distress and many view themselves contemptuously.<sup>204</sup> This resonates with the experiences described by many of the participants in the present study. Their accounts included panic, low confidence, fear and feelings of social exclusion. Disclosure of low literacy was rare and the limited engagement and interactions with healthcare staff were reported to have been influenced by felt rather than enacted stigma.

Wright et al.<sup>212</sup> explored the question posed by Link et al. which was: "*Does the effect of stigma endure because rejection by others continues unabated or is it the trauma and pain of past rejection that stays with the stigmatised person?*"<sup>216</sup> Link et al. developed modified labelling theory, which assumes that being diagnosed or labelled with a stigmatising condition, (mental illness in the Wright study), results in a spoiled identity and this is linked to

negative outcomes in terms of unemployment, economic success, social functioning and self-esteem. It is assumed these negative outcomes are not due solely to mental illness but to being placed in a highly stigmatised role.<sup>212</sup>

Participant accounts emphasised the stigmatised role. The stress of having to perform literacy activities were reported and linked to low literacy but the stigma and 'past rejection' experienced in childhood had reportedly influenced and continued to influence feelings of low self-esteem; disclosure management strategies; and social interactions. Few examples of enacted stigma in adulthood were reported but the influence of past rejection appeared to also prevent opportunities to gain help to reduce the stress caused by low literacy itself.

The following sets out the social psychological mechanisms that account for labelling effects according to modified labelling theory. I have inserted low literacy as the stigmatising condition to illustrate these assumptions:

- ❑ It is assumed that persons with [low literacy] along with members of the general population internalise cultural conceptions of what it means to have [low literacy]
- ❑ The idea that persons with [low literacy] are generally thought poorly of and likely to be discriminated against is a significant element of these cultural conceptions
- ❑ For people who are officially labelled, beliefs regarding [those with low literacy] become relevant
- ❑ People who believe most strongly in the low opinion of society may suffer deficits in employment, income, self-concept.<sup>212</sup>

It would appear, then, that participants' own stigma consciousness not only affected their mental health and wellbeing but also was often the main influence on their interactions in various social contexts including the healthcare environment. These considerations, however, focus on the individual with the stigmatising condition, in this case, the person with

low literacy. In order to understand and address the issues which label and separate such individuals, it is important to view these in a wider social context.

### ***7.5.2 Institutional disablement***

As introduced in Chapter 4, more recent research on stigma has emphasised the role of discrimination, shifting the focus from the individual with the distinguishing feature to the wider society.<sup>182</sup> Link and Phelan identified three generic mechanisms to achieving such outcomes: the discrimination that operates through the stigmatised person's beliefs and behaviours; individual mechanisms; and structural discrimination.<sup>184</sup> Structural discrimination is the particular focus of the Social Model of Disability.

The Social Model of Disability, mentioned previously, states that the poverty, disadvantage and social exclusion experienced by many disabled people is not inevitable and is not solely the result of their impairments or medical conditions, as a medical model would imply.<sup>56</sup> Differences in the structure and function of some areas of the brain have been identified when comparing dyslexic and non-dyslexic individuals. These neurological differences affect literacy skills, reducing the ability to perform some of the processes required to read and write.<sup>111</sup> However, these literacy problems are not themselves purely biological because reading and writing are associated with situated social practices. Differences in prevalence rates across countries confirm the social context of such skills. Dyslexia prevalence varies with the complexity of languages. Countries with regular languages, for example, Finnish or Serbo-Croatian, where written letters consistently map to sounds, have a lower prevalence of dyslexia than countries with irregular languages e.g. English where complex mapping from letters to sounds is required and spelling rules are ambiguous and difficult to learn.<sup>111</sup> Engagement in literacy activities is required to function day to day in a developed society because of the way that many social practices are constructed. I would argue that it is the construction of relevant social practices, such as accessing health services, that creates potential social and institutional barriers to appropriate healthcare and self-care.

As already suggested in Chapter 1, structural factors likely to hamper the engagement with and development of health literacy among patients with low literacy exist within the health service. The two main examples were the extensive reliance on written information, and the lack of awareness of healthcare staff with regard to potential low literacy. Participants' accounts supported the existence of these two structural barriers to health. In particular, the lack of awareness of healthcare staff is important not only in their assumptions that patients are able to engage in the required literacy activities but also in their lack of sensitivity to the plight of those with low literacy, their feelings of stigma and the need to avoid labelling. In order to remove these barriers, healthcare staff need to be part of a literacy sensitive health service and this is revisited in the discussion of solutions and implications for policy and practice below.

Literacy activities within the NHS are mainly set in terms of volume, format and level of difficulty by educated professionals and from the accounts in this study patients with low literacy are likely to be passive in the implementation of these activities. It has been suggested in the literature that there is a need to reframe stigmatisation and discrimination to conceptualise them as social processes that can only be understood in relation to broader notions of power and domination. Parker and Aggleton described stigma and discrimination as ultimately being linked to the workings of social inequality and taking shape in specific contexts of culture and power. They proposed that there is a need to think more broadly about how some individuals and groups come to be socially excluded and about the forces that create and reinforce exclusion in different settings.<sup>176</sup> In the present study, as already discussed, many participants described stereotypical views of healthcare staff, of doctors in particular. This has been designated as reverse stigmatisation.<sup>184</sup> Power differences in the doctor-patient relationship, however, mean that doctors do not end up as a stigmatised group or suffer discrimination. Other similar circumstances have been described. For example, prison inmates are unable to act with discriminatory consequences towards prison guards because they do not have the social, political and economic power.<sup>184</sup>

Passivity and lack of power have possibly been exacerbated by the hidden nature of low literacy and the shame attached to it. Just as people with low literacy do not benefit from a common identity, they are also not politicised as a group, unlike other groups that have embraced and campaigned in the name of the Social Model of Disability. Their lack of visibility or collective action has potentially left them in a position where the role of society in their social exclusion remains unrecognised.

Many of the participants in the present study appeared to share the perspective that their low literacy and associated issues were attached to them as individuals, describing the impact on their education and in relation to the social practices in which they engaged, including those in healthcare contexts. Some participants did demonstrate some insight into what might need to change in terms of education or health, for example, Margaret highlighted the need for training across the health service so that healthcare staff would be aware of dyslexia and the problems relating to it. Fraser displayed strong feelings that the education system did not provide appropriate support for people with dyslexia. However, his political stance related solely to education. His ideas for any health service change were for increased awareness of the need for treatment of problems such as people having their eyesight checked in relation to their potential dyslexia. This may reflect his personal experiences. These perspectives suggest that the issues and problems associated with low literacy remain in the ownership of the individuals in question. The capabilities approach, discussed next, provides a useful perspective on the issues for individuals with low literacy. This perspective is revisited later in this chapter in considering implications for policy and practice.

### ***7.5.3 Capabilities and functioning***

The capabilities approach, proposed by Sen and developed in collaboration with others to assess a person's advantage and disadvantage (*The Idea of Justice*, pp.296-297)<sup>217</sup> provides a useful perspective on the interactions between people with low literacy and their

social environment. Sen described the concept of ‘functionings’ as one that “*reflects the various things a person may value being and doing.*” (*Development as Freedom*, p.75)<sup>218</sup> He defined ‘capabilities’ as combinations of functionings that are feasible for a person to achieve, adding that capabilities could be considered as a kind of freedom to achieve alternative functioning combinations, or various lifestyles. (*Development as Freedom*, p.75)<sup>218</sup>

Literacy is a widely valued functioning that contributes significantly to capabilities for many other valued functionings, including those related to social status and health. Participants did not focus on literacy skills in their own right as intrinsically valuable. Their accounts suggested that literacy skills were instrumentally valuable in the two broad areas highlighted in the reasons participants gave for their engagement with literacy learning. Firstly, for being able to engage in literacy-related social practices, particularly in relation to being able to secure and maintain paid employment, with associated implications for social inclusion. Secondly, literacy was valued by participants in relation to personal social practices such as reading to their children or helping them with homework. These findings shift the emphasis from literacy itself to the capability sets which require literacy as a functioning.

In examining the relationship between functional literacy and health literacy in Chapter 1, I suggested that the former was a prerequisite for the latter. The relevant issues therein can be illustrated in the context of functionings and capabilities. Sen indicated that there is a difference between “*realised functionings*” (what the individual actually does) and the capability set of alternatives that an individual has, referring to the capability set as the things a person is substantively free to do. (*Development as Freedom*, p.75)<sup>218</sup> Health literacy, however it is defined, could be considered as a functioning which adds to the capability set of being healthy and/or as a capability that depends on a set of functionings which includes literacy skills. Two points made earlier in this thesis were that: low health literacy is more prevalent than low functional literacy in the general population; and an individual's need for health literacy varies according to health status, among other things. Those with the realised

functioning of basic functional literacy are more able than those with low literacy to achieve the capability of health literacy when the need arises.

Sen highlighted the role of public policy in enhancing capabilities and including an element of empowerment by stating that *“the direction of public policy can be influenced by the effective use of participatory capabilities by the public.”* (*Development as Freedom*, p.18)<sup>218</sup>

As already mentioned, people with low literacy are not politically organised in any way. Although the notion of health literacy as a community resource<sup>57</sup> may be useful in considering political action as a community which may include members with low literacy, those concerned are unlikely to wish to be identified as such and their needs may not be considered specifically. This places a greater responsibility on organisations such as the NHS to remove the institutional barriers, such as the over reliance on written information so that the capability of health literacy can be achieved with a set of functionings that does not necessarily include complex literacy activities. Overall, this study has provided an insight into other barriers and issues from the perspective of people with low literacy.

## ***7.6 What this study has added***

Most of the research focusing on literacy and health has been carried out in the USA. This study presents a UK perspective through first-hand accounts from people with low literacy.

The present study has gone beyond the obvious in two ways. Firstly, it has confirmed the existence of a hidden population with low literacy whose members often make great efforts to ensure that their difficulties are not obvious to others including healthcare professionals. Having identified, through a systematic review, associations between low literacy and poor health in this hidden population, the primary research has documented accounts which suggest that low literacy has an influence on the health of the individual concerned through various social practices such as attending a healthcare consultation or carrying out self-care activities. The findings help to explain some of the associations evidenced in the considerable body of literature relating to health literacy and health outcomes, most of which



consists of cross-sectional and quantitative studies. Secondly, this study has explored the life histories and the effects on mental wellbeing that participants attribute to their low literacy or imply through their accounts, and it has provided greater insight than previously published on the effects of stigma on health and self-care; and social relationships, including those with healthcare staff. Many of the issues are modifiable and several potential courses of action for healthcare providers have been identified.

The social practice view is particularly useful in examining the findings in terms of literacy-related practices within the health service; literacy events that take place within these practices; and the demands these practices and events make on patients' literacy skills. The study has highlighted that, to address the issues for this population, the more obvious solutions of simplifying written information and using pictures or other media, thus reducing the demand in terms of literacy skills, are not adequate measures in themselves. Communication and relationships between healthcare staff and participants as patients may be jeopardised by stigmatising processes and social barriers. In the existing literature, shame and stigma are mainly referred to in support of the proposal that people with low literacy are likely to conceal their difficulties but the wider implications of these feelings of shame have largely been neglected in the body of health literacy research. This study has highlighted the role that fear of stigma and associated information control has on those with low literacy in terms of their interactions with healthcare staff and others and their likelihood of seeking help with understanding clinical information, with self-management activities and in their social and mental wellbeing.

While many of the issues around disclosure can be more readily associated with the hidden population, those in relation to accessing and using written information will apply to the wider population, particularly some of the groups excluded from this research such as people with other primary languages or those with cognitive impairment. My rationale for focusing on the hidden population was based on the concealment of the problem and so, the lower likelihood of having healthcare staff offer extra support such as oral explanations or ensuring that their

instructions for self-care were understood. It should not be assumed, however, that any or all of these extra support activities consistently feature in clinical encounters with those who have more obvious literacy or language difficulties. The issues which are associated with literacy activities will potentially be issues for this much broader population. Indeed, it could be argued that addressing communication issues in particular has the potential to benefit the general patient population.

As well as providing insight into the pathways between low literacy and poor health, this study has added to the body of stigma research, which has mainly focused on race, medical conditions such as epilepsy, or physical disfigurements. This study has highlighted the evidence for low literacy as a stigmatising condition and has demonstrated the similarities with other conditions of interest in the existing stigma research literature as well as the influence that the associated stigma has on the social interactions and mental health and wellbeing of those with low literacy.

Participant accounts in the present study have provided insight into experiences of stigma at a local level as recommended by Kleinman and Hall-Clifford who contended that the study of stigma has focused too heavily on psychological approaches and has neglected to incorporate stigma and stigmatised in local moral contexts. They emphasised the need to understand the unique cultural and social processes that create stigma in the lived world of the stigmatised, proposing that such a focus is a step towards combating stigma.<sup>177</sup>

The identification of pathways between low literacy and poor health; the issues in relation to required literacy activities for healthcare and self-care; the role of stigma; and the proposed solutions for healthcare providers all need to be considered in terms of the implications they have for health service providers and for policy makers. These are discussed next.

## ***7.7 Implications for policy and practice***

While there is an apparent need for improvements in education, the NHS also needs to respond to adults who have left formal education with low literacy. Given the estimated prevalence of low literacy in the UK, most frontline clinical staff are likely to encounter people with literacy difficulties every day. Several implications for both NHS policy and practice can be gleaned from the findings of this study. These can be considered in six broad areas: the need for agencies other than education departments to respond to people with low literacy; the potential harm rather than benefit for patients of literacy screening in clinical settings; the NHS agenda of asset based approaches and patients as partners; the need to improve communication and relationships in order to achieve these; the need to be sensitive to the effects of stigma on those with low literacy; and the potential to enhance their capabilities.

It has been proposed that the best response to low levels of literacy in a population is to improve access to effective school education and provide adult education for those who missed out.<sup>51</sup> While this is undoubtedly a commendable vision, as far as adult education is concerned, there is evidence of: low recognition among adults of the need for improved literacy;<sup>5, 9</sup> a small proportion among those in need who take up adult education;<sup>9</sup> and evidence from participants in the present study that initial engagement is fraught with fears of having to disclose, fear of stigma and worry over coping with learning in general.

All of these would appear, at least for the foreseeable future, to necessitate a response that builds on provision and promotion of adult learning but also involves other agencies such as the NHS acknowledging adult literacy levels as they are and addressing these in a number of ways. While referral of patients to adult learning itself may be an option for healthcare staff, this would essentially be limited due to the low levels of disclosure and the absence of literacy screening in clinical settings.

Screening for literacy problems in healthcare environments may appear to be a potentially helpful solution, but this is not practical in many clinical situations. Some of the health literacy measures are fairly time consuming, although the NVS is said to take only 3 minutes to complete suggesting that it is of sufficient brevity for clinical use.<sup>219</sup> Baker proposed that, before implementing literacy screening, staff should be trained about the extreme shame that those with low literacy feel and that they should know how to address the topic sensitively.<sup>194</sup> More recently, others have re-iterated the potential for harm in the form of shame and alienation.<sup>220, 221</sup> Paasche-Orlow et al. recommended that literacy screening was not appropriate since no screening programme for limited literacy had been shown to be effective. They further claimed that the evidence for potential harm outweighs the benefits.<sup>220</sup>

In contrast with these findings, it has been claimed that patients with low literacy were strongly supportive of literacy screening,<sup>81, 222</sup> although one study declared that patients with low literacy were comfortable<sup>222</sup> and the other, anxious<sup>81</sup> about the literacy screening. There appears to be no consensus on the subject to date, and acceptability of literacy screening may vary across population groups or settings and may depend on how it was carried out. The use of screening instruments was not discussed in the present study but several participants indicated that they would not want their low literacy to be highlighted in their medical notes. Some who said that it would be helpful to have a flag in their notes added that it may not be acceptable to everyone. Again this suggested that the issue of low literacy would be best addressed through the universal approach of a literacy sensitive health service, the need for which is evident both from the findings of this study and from an examination of current health policy.

In Scotland and, similarly, in the rest of the UK, current government policy in relation to health and tackling health inequalities emphasises the role of the patient in several ways. The Equally Well Action Plan, aimed at tackling health inequalities, placed an emphasis on anticipatory care and self-care.<sup>19</sup> Co-production, a term which originated in the US,<sup>223</sup> and refers to working with patients as partners to deliver health, has become a central feature of

government policy on the health of the population,<sup>224</sup> and on the quality of healthcare.<sup>225</sup> The recently published report on the Commission on the Future Delivery of Public Services re-iterated the importance of patient involvement and the need to “*maximise talents and resources, support self reliance and build resilience.*” The commission recommended the achievement of collaborative working, working *with* people, rather than *for* them and thus employing asset-based approaches.<sup>226</sup>

An asset-based approach in a healthcare context means that staff and patients are considered as assets and both work jointly to deliver or produce health. The concept of social capital has also emerged as central to the asset-based approach. Social capital is concerned with social networks such as people’s sense of belonging to their community, community co-operation, reciprocity and trust, and civic engagement.<sup>227</sup> However, the need to be sensitive to those with low literacy becomes evident in considering such approaches, considering the stigmatisation and feelings of isolation and social exclusion expressed by participants in the present study.

The felt and enacted stigma that were identified among people with low literacy is similar to that experienced by others, for example people with mental health problems or lesbian, gay or bisexual (LGB) people.<sup>228</sup> There is an opportunity to address their needs similarly, through the NHS Equality and Diversity agenda and the Single Equality Schemes of NHS Boards.<sup>229</sup> While the population with low literacy fits the profile of the population groups which have been given a particular focus in developing the national NHS Equality Schemes, the low literacy group is less visible, both in practical and strategic terms. Raising awareness among healthcare staff of the size and nature of the problem and the particular issues related to low literacy may help change the ‘master narratives,’<sup>203</sup> about those with low literacy.

While literacy awareness among staff may help promote an understanding of potential problems, staff becoming ‘wise,’ as Goffman described those who are aware of potential

stigma associated with an individual,<sup>175</sup> does not mean that those with low literacy are happy to disclose to those healthcare staff. It remains important that any response to the patient with low literacy is acceptable to the individual concerned, particularly if they do not want to acknowledge their low literacy and that healthcare staff avoid 'outing' the patient against the patient's wishes.

Solutions relating to written information need to be universal rather than, for example, having alternative simple versions of leaflets available. It has been demonstrated, however, that even with the simplest materials, patients with low literacy do not comprehend as well as those with higher literacy<sup>230</sup> and better oral communication and explanations are still likely to be needed. Pictures have also been shown to improve communication and to increase comprehension, recall and adherence<sup>231, 232</sup> and participants in the present study made several suggestions about the use of pictures, particularly to help with taking medication. Universal solutions, nevertheless, have the potential to be unacceptable to people with adequate literacy, who may feel insulted if help were to be offered or any suggestion that they may not be able to engage in the necessary literacy activities required to process health information or perform self-care.

The idea that health can be a partnership between staff and patients requires that communication and relationships with those with low literacy improve, otherwise their ability to co-produce health as partners will be seriously impaired. Initiatives and practices within the health service require to focus on simplified communication; fewer 'on the spot' literacy activities; new technologies; and ways of avoiding the need to disclose low literacy all need to be considered as ways of imparting the necessary health information. There is significant scope for health services to reduce the extent to which effective self-care and healthcare depend on complex literacy activities. For example, performing a "*literacy walk through*" which involves evaluating what literacy skills are needed to participate in a visit to a healthcare establishment has been recommended.<sup>233, 234</sup>

The wider aspects of health literacy are more difficult to address but many of these could be viewed from the perspective of enhancing individuals' capabilities. For example, the patient support group, which tends to focus on those with long term conditions, has been offered as an example of an asset-based approach. As already discussed, as they stand, patient support groups are less likely to be attractive to, or to benefit patients with low literacy. Such approaches require to be set up and implemented in a literacy sensitive manner and to offer ways of enhancing the capabilities of the individuals concerned in participating in the management of their own health and health conditions, including decision-making.

There is a body of evidence demonstrating the benefits of shared decision making with an emphasis on the need for appropriate information to facilitate this.<sup>235, 236</sup> As discussed, it would be helpful to examine the literacy activities required for patients to gain clinical information to help this process. However, participation in decision-making requires more than clinical information and it has been demonstrated that patients' perceptions of their involvement is related to the communication and relationships they have with the healthcare staff concerned.<sup>118</sup> As the present findings illustrated, those with low literacy are unlikely to view themselves as partners in the process; may not readily engage in the consultation if they are worried about disclosure; and may not ask questions or seek support in making decisions or preparing for taking forward care and treatment of health conditions. For those with low literacy, enhancing the capability of being healthy may thus involve addressing relationships with healthcare staff in order to improve the 'functioning' of decision-making.

The use of Ask Me 3<sup>171</sup> and Teach-back<sup>172</sup> as potential ways of addressing the desire for simple explanations, expressed by so many participants in the present study and could help ensure understanding of procedures for self-care. These techniques may provide solutions which will also enhance relationships with healthcare staff, if those with low literacy are enabled to contribute more to the interaction and gain appropriate explanations and support to make decisions or manage their own health conditions.

In general, the process of addressing the issues for people with low literacy through policy and practice would benefit from further research and robust evaluation of potential solutions.

### ***7.8 Implications for future research***

As with the general body of health literacy research, the testing and evaluation of initiatives to improve health literacy or improve outcomes for those with low literacy have been mainly carried out in the US. Pilot interventions in clinical settings in the UK would help to test appropriate approaches to improving the healthcare and self-care experiences and outcomes for people with low literacy. The findings of this study have highlighted particular issues through first-hand accounts of people with low literacy with particular reference to the UK health system. While some suggestions for service improvements need not be tested, for example, the colour coding within the hospital environment, or awareness raising among healthcare staff, others would benefit from piloting and robust evaluation. These could include the use of AskMe3 and/or Teachback in clinical departments. As well as evaluating outcomes, research should focus on the acceptability of interventions to people with low and those with higher literacy levels. The capabilities approach may provide a useful evaluative lens through which to judge changes in the experiences of those with low literacy in health contexts.

### ***7.9 Conclusion***

This study has highlighted the various ways that people with low literacy struggle with written and spoken communication in clinical encounters and in self-care activities as well as the impact that literacy and associated stigma have on the social and mental wellbeing of those concerned. These, along with patients' coping strategies and the lack of awareness among healthcare providers of potential literacy issues for patients may jeopardise clinical benefit. Unless the problem of low literacy is acknowledged and addressed by the NHS, general efforts to improve health and reduce social inequalities in health are unlikely to achieve their



full potential. The findings of this study present potential solutions for service providers. These would benefit from piloting and evaluation to help create a literacy-sensitive health service, which is likely to improve engagement; enable self-care activity and enhance the capability of being healthy in those with low literacy.

And so I return to the words of Amartya Sen, with which I began this thesis:

*“Not to be able to read or write or count or communicate is itself a tremendous deprivation. And if the person is thus reduced by illiteracy and innumeracy we can not only see that the person is insecure to whom something terrible could happen, but more immediately, that to him or her something terrible has actually happened”<sup>4</sup>*

It is clear from the findings of this study that, for many of those with low literacy, ‘something terrible’ happened early in their lives in the form of stigmatisation, discrimination and exclusion and for many, the ‘something terrible’ has continued to happen in adulthood both in the workplace and in social situations. Participants’ accounts suggested insecurity and fear of being identified as having low literacy and subsequently stigmatised. In Maslow’s hierarchy of needs,<sup>237</sup> security is near the bottom of the pyramid along with other basic needs.

As a society, prevention of this deprivation and insecurity needs to be tackled through improvements in the education system, recognising children who may have dyslexia or other reading problems and ensuring that literacy standards are met by all children. However, for the thousands of adults whose literacy levels mean that they are struggling to engage in relevant social practices, it is too late as far as formal education is concerned. The responsibility to alleviate the problems associated with low literacy must lie with the organisations and public services, such as the NHS, so that socially constructed barriers for those with low literacy are removed and their capabilities are enhanced so that they are able to engage in both necessary and chosen social practices.

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## ***Appendix 1: MEDLINE search strategy***

1. (ability adj2 read\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
2. (read\$ adj2 skill\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
3. TOFHLA\$.mp.
4. Newest Vital Sign.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
5. WRAT\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
6. (REALM and "rapid estimate").mp. [mp=title, original title, abstract, name of substance word, subject heading word]
7. numeracy.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
8. literacy.mp.
9. \*Educational Status/
10. or/1-9
11. exp Hospitalization/ or exp Patient Admission/
12. exp Health Knowledge, Attitudes, Practice/ or exp Attitude to Health/
13. exp self care/ or exp blood glucose self-monitoring/ or exp self administration/ or exp self medication/
14. compliance.mp. or exp Patient Compliance/
15. exp Self Medication/
16. exp Disease Management/
17. exp Health Services Accessibility/ or exp Health Status/
18. exp Primary Prevention/
19. exp Health Behavior/
20. exp Preventive Medicine/ or exp Preventive Health Services/ or exp Health Promotion/
21. exp Chronic Disease/ or long term condition\$.mp.
22. or/11-21
23. Epidemiologic studies/
24. exp case control studies/
25. exp cohort studies/
26. Case control.tw.
27. (cohort adj (study or studies)).tw.
28. Cohort analy\$.tw.
29. (Follow up adj (study or studies)).tw.
30. (observational adj (study or studies)).tw.
31. Longitudinal.tw.

32. Retrospective.tw.
33. Cross sectional.tw.
34. Cross-sectional studies/
35. or/23-34
36. Randomized Controlled Trials/
37. randomized controlled trial.pt.
38. Random Allocation/
39. Double Blind Method/
40. Single Blind Method/
41. clinical trial.pt.
42. exp Clinical Trials/
43. (clinic adj trial\$1).tw.
44. ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3)).tw.
45. randomly allocated.tw.
46. (allocated adj2 random).tw.
47. case report.tw.
48. historical article.pt.
49. review of reported cases.pt.
50. review, multicase.pt.
51. or/36-46
52. or/47-50
53. 51 not 52
54. interview\$.mp.
55. experience\$.mp.
56. qualitative.tw.
57. focus group\$.mp.
58. or/54-57
59. (systematic adj review\$).tw.
60. (published adj studies).ab.
61. (data adj extraction).ab.
62. meta-analysis.ti.
63. meta-analysis/
64. (data adj synthesis).tw.
65. comment.pt.
66. letter.pt.
67. editorial.pt.
68. or/59-64
69. or/65-67

- 70. 68 not 69
- 71. 35 or 53 or 58 or 70
- 72. exp Developing Countries/ or developing nation\$.mp.
- 73. \*Ethnic Groups/
- 74. \*Residence Characteristics/
- 75. \*Nursing Staff, Hospital/ or \*Dental Staff, Hospital/ or \*Medical Staff, Hospital/ or \*Dental Staff/ or \*Medical Staff/ or \*Nursing Staff/
- 76. \*Students, Premedical/ or \*Students, Nursing/ or \*Students, Dental/ or \*Students, Medical/ or \*Students, Public Health/ or \*Students, Health Occupations/ or \*Students, Pharmacy/
- 77. \*Child/
- 78. \*Mothers/
- 79. \*Fathers/
- 80. \*Parents/
- 81. \*Adult/
- 82. or/78-81
- 83. 77 and 82
- 84. 77 not 83
- 85. \*Pattern Recognition, Visual/ or \*Dementia/ or \*Brain Damage, Chronic/ or cognit\$.mp.
- 86. \*Brain Injuries/
- 87. (or/72-76) or (or/84-86)
- 88. (10 and 22 and 71) not 87

## ***Appendix 2: CINAHL search strategy***

1. (ability adj2 read\$).mp. [mp=title, subject heading word, abstract, instrumentation]
2. (read\$ adj2 skill\$).mp. [mp=title, subject heading word, abstract, instrumentation]
3. TOFHLA\$.mp.
4. Newest Vital Sign.mp. [mp=title, subject heading word, abstract, instrumentation]
5. WRAT\$.mp. [mp=title, subject heading word, abstract, instrumentation]
6. (REALM and "rapid estimate").mp. [mp=title, subject heading word, abstract, instrumentation]
7. numeracy.mp. [mp=title, subject heading word, abstract, instrumentation]
8. literacy.mp.
9. \*Educational Status/
10. or/1-9
11. exp Patient Admission/
12. exp Health Knowledge/
13. exp Health Behavior/
14. exp Attitude to Health/
15. exp Self Care/
16. self care/ or exp blood glucose self-monitoring/ or exp self medication/
17. exp self care/ or exp blood glucose self-monitoring/ or exp self administration/ or exp self medication/
18. exp PATIENT COMPLIANCE/
19. exp SELF MEDICATION/
20. exp Disease Management/
21. exp Health Status/
22. exp Health Services Accessibility/
23. exp Health Behavior/
24. exp Health Promotion/
25. exp Chronic Disease/ or long term condition\$.mp.
26. or/11-25
27. Prospective Studies/
28. exp Case Control Studies/
29. Correlational Studies/
30. Nonconcurrent Prospective Studies/
31. Cross Sectional Studies/
32. (cohort adj (study or studies)).tw.
33. (observational adj (study or studies)).tw.
34. or/27-33
35. exp Clinical Trials/

36. clinical trial.pt.
37. (clinic\$ adj trial\$1).tw.
38. ((singl\$ or doubl\$ or trebl\$ or tripl\$) adj (blind\$3 or mask\$3)).tw.
39. randomi?ed control\$ trial\$.tw.
40. Random Assignment/
41. random\$ allocat\$.tw.
42. quantitative studies/
43. allocat\$ random\$.tw.
44. or/35-43
45. qualitative studies/
46. ethnographic research/
47. phenomenological research/
48. ethnonursing research/
49. grounded theory/
50. exp qualitative validity/
51. purposive sample/
52. exp observational methods/
53. content analysis/ or thematic analysis/
54. constant comparative method/
55. field studies/
56. theoretical sample/
57. discourse analysis/
58. focus groups/
59. phenomenology/ or ethnography/ or ethnological research/
60. or/45-59
61. (qualitative or ethnon\$ or phenomenol\$).tw.
62. (grounded adj (theor\$ or study or studies or research)).tw.
63. (constant adj (comparative or comparison)).tw.
64. (purpos\$ adj sampl\$).tw.
65. (focus adj group\$).tw.
66. (emic or etic or hermeneutic\$ or heuristic or semiotics).tw.
67. (data adj2 saturat\$).tw.
68. (participant adj observ\$).tw.
69. (heidegger\$ or colaizzi\$ or spiegelberg\$).tw.
70. (van adj manen\$).tw.
71. (van adj kaam\$).tw.
72. (merleau adj ponty\$).tw.
73. (husserl\$ or giorgi\$).tw.

74. (field adj (study or studies or research)).tw.
75. lived experience\$.tw.
76. narrative analysis.tw.
77. (discours\$ adj analysis).tw.
78. human science.tw.
79. life experiences/
80. exp cluster sample/
81. or/45-80
82. meta analysis/
83. systematic review/
84. systematic review.pt.
85. (metaanaly\$ or meta-analy\$).tw.
86. metanal\$.mp. [mp=title, subject heading word, abstract, instrumentation]
87. nursing interventions.pt.
88. (review\$ or overview\$).ti.
89. literature review/
90. exp literature searching/
91. cochrane\$.tw.
92. (synthes\$ adj3 (literature\$ or research\$ or studies or data)).tw.
93. (medline or medlars or embase or scisearch or psycinfo or psychinfo or psyclit or psychlit).tw,sh.
94. pooled analy\$.tw.
95. ((data adj2 pool\$) and studies).tw.
96. ((hand or manual\$ or database\$ or computer\$) adj2 search\$).tw.
97. reference databases/
98. ((electronic\$ or bibliographic\$) adj2 (database\$ or data base\$)).tw.
99. (review or systematic-review or practice-guidelines).pt.
100. (review\$ or overview\$).ab.
101. (systematic\$ or methodologic\$ or quantitativ\$ or research\$ or literature\$ or studies or trial\$ or effective\$).ab.
102. 99 and 101
103. ((review\$ or overview\$) adj10 (systematic\$ or methodologic\$ or quantitativ\$ or research\$ or literature\$ or studies or trial\$ or effective\$)).ab.
104. or/82-98,102-103
105. editorial.pt.
106. letter.pt.
107. case study.pt.
108. record review/
109. peer review/

110. (retrospective\$ adj2 review\$).tw.
111. (case\$ adj2 review\$).tw.
112. (record\$ adj2 review\$).tw.
113. (patient\$ adj2 review\$).tw.
114. (patient\$ adj2 chart\$).tw.
115. (peer adj2 review\$).tw.
116. (chart\$ adj2 review\$).tw.
117. (case\$ adj2 report\$).tw.
118. case studies/
119. or/105-118
120. 119 not (119 and 104)
121. 104 not 120
122. 34 or 44 or 81 or 121
123. exp Developing Countries/ or developing nation\$.mp.
124. \*ETHNIC GROUPS/
125. \*IMMIGRANTS/
126. \*NURSING STAFF, HOSPITAL/ or \*MEDICAL STAFF/ or \*MEDICAL STAFF, HOSPITAL/
127. \*Students/
128. \*CHILD/
129. \*Mothers/
130. \*Fathers/
131. \*Parents/
132. \*ADULT/
133. or/129-132
134. 128 and 133
135. 128 not 134
136. \*DEMENTIA/
137. \*Brain Injuries/
138. \*COGNITION DISORDERS/ or \*COGNITION/
139. (or/123-127) or (or/135-138)
140. (10 and 26 and 122) not 139



### ***Appendix 3: British Nursing Index search strategy***

1. literacy.mp.
2. (ability adj2 read\$).mp. [mp=ti, ab, hw]
3. (read\$ adj2 skill\$).mp. [mp=ti, ab, hw]
4. TOFHLA\$.mp.
5. Newest Vital Sign.mp. [mp=ti, ab, hw]
6. WRAT\$.mp. [mp=ti, ab, hw]
7. (REALM and "rapid estimate").mp. [mp=ti, ab, hw]
8. numeracy.mp. [mp=ti, ab, hw]
9. educational status.mp. [mp=ti, ab, hw]
10. or/1-9
11. exp Patients Admission/
12. exp life style/ or exp health attitudes/
13. self care/ or exp self medication/
14. exp Patients Compliance/
15. exp Chronic Illness/ or long term condition\$.mp.
16. chronic disease.mp.
17. health status.mp.
18. access\$.mp.
19. prevent\$.mp.
20. exp Health Promotion/
21. or/11-20
22. case-control.mp.
23. cross-sectional.mp.
24. prospective stud\$.mp. [mp=ti, ab, hw]
25. cohort stud\$.mp. [mp=ti, ab, hw]
26. follow-up stud\$.mp. [mp=ti, ab, hw]
27. longitudinal stud\$.mp. [mp=ti, ab, hw]
28. retrospective stud\$.mp. [mp=ti, ab, hw]
29. observational.mp. [mp=ti, ab, hw]
30. or/22-29
31. ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3)).tw.
32. randomized controlled trial.mp.
33. experimental design.mp. [mp=ti, ab, hw]
34. research design.mp. [mp=ti, ab, hw]
35. or/31-34
36. interview\$.mp.

37. experience\$.mp.
38. qualitative.tw.
39. focus group\$.mp.
40. or/36-39
41. (systematic adj review\$).tw.
42. (published adj studies).ab.
43. (data adj extraction).ab.
44. meta-analysis.ti.
45. meta-analysis/
46. (data adj synthesis).tw.
47. or/41-46
48. 30 or 35 or 40 or 47
49. (ethnic adj minorit\$).mp. [mp=ti, ab, hw]
50. immigrants.mp. [mp=ti, ab, hw]
51. developing nation\$.mp. [mp=ti, ab, hw]
52. or/49-51
53. (10 and 21 and 48) not 52

## ***Appendix 4: EMBASE search strategy***

1. (ability adj2 read\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name]
2. (read\$ adj2 skill\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name]
3. TOFHLA\$.mp.
4. Newest Vital Sign.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name]
5. WRAT\$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name]
6. (REALM and "rapid estimate").mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name]
7. numeracy.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name]
8. literacy.mp.
9. educational status.mp.
10. or/1-9
11. exp Hospital Admission/
12. exp health status/
13. exp Health Behavior/
14. exp Attitude to Health/
15. exp self care/
16. adherence.mp.
17. compliance.mp.
18. exp Disease Management/
19. exp Health Care Access/
20. exp PREVENTION/ or exp PRIMARY PREVENTION/
21. exp PREVENTIVE HEALTH SERVICE/
22. exp Chronic Disease/ or long term condition\$.mp.
23. or/11-22
24. Clinical Study/
25. Case Control Study/
26. Family Study/
27. Longitudinal Study/
28. Retrospective Study/
29. Prospective Study/
30. Cohort Analysis/
31. (cohort adj (study or studies)).mp.

32. (case control adj (study or studies)).tw.
33. (follow up adj (study or studies)).tw.
34. (observational adj (study or studies)).tw.
35. (epidemiologic\$ adj (study or studies)).tw.
36. (cross sectional adj (study or studies)).tw.
37. or/24-36
38. controlled-study.sh.
39. crossover-procedure.sh.
40. double-blind-procedure.sh.
41. phase-3-clinical-trial.sh.
42. randomized-controlled-trial.sh.
43. single-blind-procedure.sh.
44. comparative study.tw.
45. (control\$ adj1 trial\$).tw.
46. cross?over\$.tw.
47. factorial\$.tw.
48. random\$.tw.
49. or/38-48
50. interview\$.mp.
51. experience\$.mp.
52. qualitative.tw.
53. focus group\$.mp.
54. or/50-53
55. exp Meta Analysis/
56. ((meta adj analy\$) or metaanalys\$).tw.
57. (systematic adj (review\$1 or overview\$1)).tw.
58. or/55-57
59. cancerlit.ab.
60. cochrane.ab.
61. embase.ab.
62. (psyclit or psychlit).ab.
63. (psycinfo or psychinfo).ab.
64. (cinahl or cinhal).ab.
65. science citation index.ab.
66. bids.ab.
67. or/59-66
68. reference lists.ab.
69. bibliograph\$.ab.

70. hand-search\$.ab.
71. manual search\$.ab.
72. relevant journals.ab.
73. or/68-72
74. data extraction.ab.
75. selection criteria.ab.
76. 74 or 75
77. review.pt.
78. 76 and 77
79. letter.pt.
80. editorial.pt.
81. 79 or 80
82. 58 or 67 or 73 or 78
83. 82 not 81
84. 37 or 49 or 54 or 83
85. exp Developing Country/ or developing nation\$.mp.
86. \*"ETHNIC AND RACIAL GROUPS"/ or \*ETHNIC GROUP/
87. \*NURSING STAFF/ or \*MEDICAL STAFF/ or \*STAFF/
88. \*DENTAL STUDENT/ or \*ALLIED HEALTH STUDENT/ or \*NURSING STUDENT/ or  
\*GRADUATE NURSING STUDENT/ or \*MEDICAL STUDENT/
89. \*Child/
90. \*Mothers/
91. \*Fathers/
92. \*Parents/
93. \*Adult/
94. 90 or 91 or 92 or 93
95. 89 and 94
96. 89 not 94
97. \*DEMENTIA/
98. \*Brain Injury/
99. \*COGNITION/
100. \*COGNITIVE DEVELOPMENT/ or \*COGNITIVE DEFECT/
101. (or/85-88) or (or/96-100)
102. (10 and 23 and 84) not 101

## ***Appendix 5: ERIC search strategy***

1. (ability adj2 read\$).mp. [mp=abstract, title, headings word, identifiers]
2. (read\$ adj2 skill\$).mp. [mp=abstract, title, headings word, identifiers]
3. health literacy.mp.
4. TOFHLA\$.mp.
5. Newest Vital Sign.mp. [mp=abstract, title, headings word, identifiers]
6. WRAT\$.mp. [mp=abstract, title, headings word, identifiers]
7. (REALM and "rapid estimate").mp. [mp=abstract, title, headings word, identifiers]
8. (measure\$ adj2 literacy).mp. [mp=abstract, title, headings word, identifiers]
9. numeracy.mp. [mp=abstract, title, headings word, identifiers]
10. exp Adult Literacy/ or Literacy/
11. or/1-10
12. exp Health Behavior/ or exp Health Programs/ or health.mp. or exp Mental Health/ or exp Health/ or exp Health Education/ or exp Health Promotion/ or exp Health Needs/ or exp Access to Health Care/ or exp Health Services/ or exp Health Activities/ or exp Health Conditions/ or exp Physical Health/
13. case-control.mp.
14. exp Followup Studies/ or exp Cohort Analysis/
15. prospective stud\$.mp. [mp=abstract, title, headings word, identifiers]
16. exp Longitudinal Studies/
17. cross-sectional stud\$.mp. [mp=abstract, title, headings word, identifiers]
18. observational.mp. [mp=abstract, title, headings word, identifiers]
19. 13 or 14 or 15 or 16 or 17 or 18
20. \*Research Design/ or \*Research Methodology/ or \*Program Effectiveness/ or randomized controlled trial.mp. or \*Medical Research/
21. ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3)).tw.
22. randomly allocated.tw.
23. (allocated adj2 random).tw.
24. or/20-23
25. interview\$.mp.
26. experience\$.mp.
27. qualitative.tw.
28. focus group\$.mp.
29. or/25-28
30. (systematic adj review\$).tw.
31. (published adj studies).ab.
32. (data adj extraction).ab.
33. meta-analysis.ti.

34. meta-analysis/
35. (data adj synthesis).tw.
36. or/30-35
37. 19 or 24 or 29 or 36
38. exp Developing Nations/
39. \*Ethnic Groups/
40. \*Immigrants/
41. \*Children/
42. \*Mothers/
43. \*Fathers/
44. \*Parents/
45. \*Adults/
46. or/42-45
47. 41 and 46
48. 41 not 47
49. 38 or 39 or 40 or 48
50. (11 and 12 and 37) not 49

## ***Appendix 6: PsycINFO search strategy***

1. (ability adj2 read\$).mp. [mp=title, abstract, heading word, table of contents, key concepts]
2. (read\$ adj2 skill\$).mp. [mp=title, abstract, heading word, table of contents, key concepts]
3. TOFHLA\$.mp.
4. Newest Vital Sign.mp. [mp=title, abstract, heading word, table of contents, key concepts]
5. WRAT\$.mp. [mp=title, abstract, heading word, table of contents, key concepts]
6. (REALM and "rapid estimate").mp. [mp=title, abstract, heading word, table of contents, key concepts]
7. numeracy.mp. [mp=title, abstract, heading word, table of contents, key concepts]
8. exp Literacy/ or literacy.mp.
9. \*Educational Attainment Level/
10. or/1-9
11. exp Health/ or exp Health Service Needs/ or exp Health Attitudes/ or exp Health Promotion/ or exp Health Care Utilization/ or exp Health Care Seeking Behavior/ or health.mp. or exp Health Behavior/ or exp Health Knowledge/ or exp Mental Health/ or Health Care Services/ or exp Health Education/ or exp Holistic Health/
12. case-control stud\$.mp. [mp=title, abstract, heading word, table of contents, key concepts]
13. exp Longitudinal Studies/
14. cross-sectional stud\$.mp. [mp=title, abstract, heading word, table of contents, key concepts]
15. exp Cohort Analysis/
16. exp Prospective Studies/
17. exp Followup Studies/
18. exp Observation Methods/
19. 12 or 13 or 14 or 15 or 16 or 17 or 18
20. limit 19 to human
21. ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3)).tw.
22. randomly allocated.tw.
23. (allocated adj2 random).tw.
24. randomized controlled trial.mp.
25. exp Experimentation/ or exp Experimental Design/ or exp Methodology/ or exp Experimental Methods/
26. or/21-25
27. interview\$.mp.
28. experience\$.mp.
29. qualitative.tw.
30. focus group\$.mp.
31. or/27-30
32. (systematic adj review\$).tw.



33. (published adj studies).ab.
34. (data adj extraction).ab.
35. meta-analysis.ti.
36. meta-analysis/
37. (data adj synthesis).tw.
38. or/32-37
39. 19 or 26 or 31 or 38
40. exp Developing Countries/ or developing nation\$.mp.
41. \*"Racial and Ethnic Groups"/
42. \*Nurses/ or \*Health Personnel/ or \*Medical Personnel/
43. \*Dental Students/ or \*Nursing Students/ or \*Medical Students/
44. children.mp.
45. \*Mothers/
46. \*Fathers/
47. \*Parents/
48. adult\$.mp.
49. or/45-48
50. 44 and 49
51. 44 not 50
52. (or/40-43) or 51
53. (10 and 11 and 39) not 52

## ***Appendix 7: ASSIA search strategy***

(KW=(case-control or cross-section\* or cohort) or KW=(prospective or longitudinal or observational) or KW=(qualitative or trial or RCT)) AND (KW=((ability WITHIN2 read\*) or (read\* WITHIN2 skill\*) or TOFHLA\*) or KW=(WRAT\* or (rapid estimate OR REALM) or literacy)) AND (KW=(hospital or health or self-care) or KW=(compliance or adherence or medication) or KW=(disease or (long-term condition))) NOT (KW=((developing countr\*) or (developing nation\*) or (ethnic group\*)) or KW=child\* and not KW=((child\* NEAR adult\*) or parent\*))

**Appendix 8: Data extraction form**

Author			
Article title			
Source and reference			
Verification of study eligibility (correct population, interventions (studies), outcome and study design)			
Target population (broad description)			
Inclusion criteria			
Exclusion criteria			
Recruitment procedures			
Characteristics of participants - Age			
Ethnicity			
Socio-economic information			
Language			
Sex	<input type="checkbox"/> Male	%	<input type="checkbox"/> Female %
Geographical region	US <input type="checkbox"/> Canada <input type="checkbox"/> Australia <input type="checkbox"/> UK <input type="checkbox"/> Other <input type="checkbox"/>		
Number of participants			
Overall response rate			
Differences between characteristics of participants and non-			

participants	
Loss to follow up	
Differences between characteristics of those completing and drop-outs	
Design of the study	RCT <input type="checkbox"/> Other trial <input type="checkbox"/> Cohort <input type="checkbox"/> Case-control <input type="checkbox"/> Cross-sectional <input type="checkbox"/> Qualitative <input type="checkbox"/>
Aim of the study	
Setting and description	Hospital inpatient <input type="checkbox"/> Hospital outpatient <input type="checkbox"/> Primary Care <input type="checkbox"/> Community <input type="checkbox"/>
Tools(s) used to measure literacy	WRAT <input type="checkbox"/> TOFHLA <input type="checkbox"/> S-TOFHLA <input type="checkbox"/> REALM <input type="checkbox"/> REALM-R <input type="checkbox"/> NVS <input type="checkbox"/> Other <input type="checkbox"/>  ABE (for qualitative) <input type="checkbox"/>
Is literacy in categories or continuum?	
Who carried out the measurement of literacy?	
What comparisons were made and numbers of each?	
Outcomes measures	
What tools were used to gather outcomes data?	
Who carried out the measurement of outcomes?	
Did the same person carry out measurement of literacy and measurement of outcomes?	Yes <input type="checkbox"/> No <input type="checkbox"/> DK <input type="checkbox"/>
How was the validity of self reported data maximised?	
Was knowledge included as a component of literacy	Component <input type="checkbox"/> Outcome <input type="checkbox"/> Neither <input type="checkbox"/>

or as an outcome?	
Statistical technique(s) used or qualitative analysis	
Was multivariate analysis carried out?	No <input type="checkbox"/> Yes <input type="checkbox"/>
What confounding variables were included in the analysis?	
What confounding variables were not included in the analysis?	
Quantitative results	
Qualitative results	
Outcome category	
Outcome summary	
Quality assessment	
Additional comments	

## ***Appendix 9: Quality assessment form for included studies***

Author .....

Title .....

Source and reference .....

	Yes	No	D/K	N/A
1. Is the study population adequately described?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Are inclusion criteria documented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Are exclusion criteria documented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Are inclusion/exclusion criteria appropriate to the questions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there evidence of/potential for selection bias?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. What is the response rate?	%			
7. What is the proportion lost to follow up?	%			
8. Were the characteristics of non-participants different from participants?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Were the characteristics of those lost to follow up different from completers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Is there evidence of/potential for response bias?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Was literacy assessed using a validated tool(s)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Are health outcomes clearly defined?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Are health outcomes measured using a valid and reliable tool?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Is there evidence of/potential for measurement bias?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Was the person measuring health outcomes blinded to the participants' literacy level?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Is there evidence of/potential for observer bias?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Is the study design appropriate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Was the sample size adequate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Are the characteristics of comparison groups similar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. Is statistical analysis adequately described?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Is adequate data presented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Has potential confounding been included in the analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Is qualitative analysis adequately described?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Are the conclusions supported by the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## ***Appendix 10: Ethics approval***

Ethics application UREC 8060, Exploring the links between low literacy and poor health

Peter Willatts [p.willatts@dundee.ac.uk]

Sent: 29 October 2008 23:35

To: Phyllis Easton [P.M.Easton@dundee.ac.uk]

Dear Phyllis,

My apologies for the delay in replying to your application. Our reviewers thought your application was well presented and provided evidence of understanding the ethical issues which may arise during the study. We suggest only one minor change to the Participant Information Sheet. Under 'Do I have to take part?' the last sentence should end with "without explanation or any negative consequences."

Your study is approved and you may begin the work.

Best wishes,

Peter Willatts,  
Chair, University Research Ethics Committee

Dr Peter Willatts  
School of Psychology, University of Dundee, Nethergate, Dundee, DD1  
4HN, UK.  
Email: p.willatts@dundee.ac.uk  
Tel: +44 (0)1382 384618; 384623  
Fax: +44 (0)1382 229993  
The University of Dundee is a registered Scottish charity, No:  
SC015096



## **Appendix 11: Participant information sheet**



### **What is the study about?**

I am carrying out a study to find out what people who need some help with literacies think about the health service and about health information.

### **What will I have to do if I take part?**

If you take part in this study I will meet with you for about an hour. I will ask you about things like going to the doctor and taking medicine.

### **What will happen to the information I give?**

Our conversation will be recorded so that I can go back over it. I will pick out the important things that you have pointed out.

Your name will not be used at any time. Everything you tell me will be confidential. I will write a report about what all the people have told me. A short report may be published in a health journal.

The report will also be shared with people who work in the health service. This will help them to find ways of making things easier for people who need help with literacies.

### **Do I have to take part?**

You do not have to take part in this study. Even if you agree to take part you can change your mind at any time. You do not have to tell us why. It will not affect any of the services or groups you are coming to.

### **Where can I get more information about the study?**

You can find out more about this study from any of the tutors at your Adult Learning Class. You can also contact me on 01382 424191 or email [phyllis.easton@nhs.net](mailto:phyllis.easton@nhs.net)

Phyllis Easton

Social Dimensions of Health Institute

University of Dundee

**Appendix 12: Participant consent form**

I agree to take part in the literacies and health study. It has been explained to

me by ..... (project worker/tutor to fill in own name)

Signed .....

### **Appendix 13: Individual interview topic guide**

The table below contains the broad topic areas to be covered during the interviews. The questions in the right hand column are example questions. Questions will be lead by the responses given and each response that highlights a difficulty or an issue to be discussed will generate probes such as:

*Tell me more about that; What did you do?; What was the outcome? etc.*

<b>Interview topic</b>	<b>Example questions</b>
<b>Introductions and warm up</b>	<p>Can you start by telling me how you came to get help with your literacies?</p> <p>Do you have anyone who regularly helps you with literacies?</p>
<b>How general health may be affected by literacy level</b>	<p>How would you say your general health is?</p> <p>Can you tell me about of any ways your literacies affect your health?</p>
<b>Self care: health information and preventive behaviour</b>	<p>Where do you normally learn about things to do with health?</p> <p>Do you attend or take part in screening?</p> <ul style="list-style-type: none"> <li>- cervical (females only)</li> <li>- breast (females over 50)</li> <li>- bowel (all over 50)</li> </ul>
<b>Self care: management of health problems; medication; family health</b>	<p>How do you get on with prescriptions?</p> <p>Do you or anyone you look after have a medical condition that needs to be treated or checked up on regularly?</p> <p>Do you have children? Tell me about what you have to do to look after their health – immunisation, childhood illnesses etc.</p>

<p><b>Access to health services: patient-healthcare provider relationships; navigating the health service environment</b></p>	<p>Does your GP know that you have some difficulties with literacies?</p> <p>If yes, how did they find out?</p> <p>Do your literacies affect whether you go to health services? If yes, how?</p> <p>Do you have anyone who helps you when you use health services?</p>
<p><b>Types of initiatives that would help access to services/self-care etc</b></p>	<p>What would make it easier for you to ..... take care of your condition/take your medicine properly (these will depend on the responses to previous questions</p> <p>How could the ..... service be improved for people with difficulties with literacies?</p>

### ***Appendix 14: Additions to individual interview topic guide***

Interview topic	Example questions
<b>Life history</b>	<p>How did you get on at school?</p> <p>When were you aware you had needed some help with your literacy?</p> <p>What sort of work have you done in the past?</p>
<b>Disclosure management</b>	<p>Who knows about your literacy?</p> <p>What did you say to them when you told them?</p> <p>How would you decide who to tell?</p>
<b>Advantages/disadvantages of disclosure</b>	<p>Do you think it matters if healthcare staff know about your literacy?</p>

## ***Appendix 15: Focus group topic guide***

This topic guide is intended as a reminder of the issues to be covered in the focus groups. These may not be discussed in the order in which they appear here and questions may vary according to the discussion within the group. Each topic will be introduced as an area which was discussed by some or all of the individual interviewees and comments invited. After comments and discussion, if perspectives revealed in individual interviews do not arise, these will be shared and further comments and discussion invited.

Access to health services e.g. appointment letters; hospital signs

Relationships with healthcare staff e.g. oral explanations; language used

Disclosure to healthcare staff e.g. who to tell; how to tell

Self-management of health conditions e.g. obtaining and using medicines

Coping strategies e.g. coping with health related literacy activities

Stigma and mental wellbeing e.g. other people's attitudes; disclosure management in general

Suggestions for the NHS to improve the experiences of people with low literacy e.g. colour coding

AskMe3

Teachback

## Appendix 16: CSO Focus on Research summary

Scottish Government Health Directorates Chief Scientist Office



# FOCUS ON RESEARCH

## EXPLORING THE LINKS BETWEEN LOW LITERACY AND POOR HEALTH. AN INVESTIGATION OF HEALTHCARE AND SELF-CARE EXPERIENCES

### Researchers

Phyllis Easton, Vikki Entwistle, Brian Williams

### Aim

To explore the links between low literacy and poor health via three research questions: 1. What are the perceived and experienced causal pathways between low literacy and poor health, as evident from the accounts of people with low literacy? 2. What resources and coping mechanisms do adults with low literacy employ to help them navigate the healthcare system and to carry out self-care activities? 3. What kinds of changes in health service provision might improve service accessibility and healthcare and self-care experiences for people with low literacy?

### Project Outline/Methodology

We conducted 25 individual interviews and 2 focus groups (9 participants) with learners from the Adult Learning Unit of Dundee City Council.

### Key Results

Participant accounts highlighted several different ways in which low literacy can impact on health, through impeding access to health services; threatening the integrity of clinical consultations and hampering self-care behaviours. Participants associated their low literacy with difficulty in using written information and in spoken conversations with healthcare staff. Some participants also saw connections between their low literacy and their low mental and social wellbeing.

Some people told staff about their literacy difficulties to cope with clinical contact and with self-care. Others reported memorising instructions. Many relied on other people to help read leaflets, organise medicines and accompany them to appointments.

Participants had a variety of suggestions for service improvement, but most focused on one of two areas: simplifying communication and making it easier or removing the need to disclose their low literacy.

### Conclusions

We have illuminated some key causal pathways that link low literacy to poor health and identified possibilities for addressing these.

### What does this study add to the field?

Existing research is mainly US based. This study presents a UK perspective through first-hand accounts from people with low literacy. It has highlighted causal links between low literacy and poorer health relevant to healthcare service provision.

### Implications for Practice or Policy

Health services do not adequately meet the needs of those with low literacy. Unless this problem is acknowledged and addressed by the NHS in Scotland, general efforts to improve health and reduce health inequalities are unlikely to achieve their full potential.

To support government policy to address health inequalities and to support people to take care of their health before they become ill, the health service needs to improve its communication, to enable people to manage their conditions and treatment, and to avoid stigmatising those with low literacy. A literacy-sensitive health service is likely to improve engagement and enable self-care activity.

### Where to next?

The Single Equality Schemes of NHS Boards provide opportunities to address these issues for people with low literacy and enhance efforts to reduce health inequalities.

Pilot interventions in clinical settings would help to identify appropriate approaches to improving the healthcare and self-care experiences and outcomes for people with low literacy. These should focus on the acceptability of interventions to people with low literacy and those with higher literacy.

### Further details from:

Phyllis Easton  
Directorate of Public Health  
NHS Tayside  
King's Cross  
Cleington Road  
DUNDEE DD3 8EA

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[www.cso.scot.nhs.uk](http://www.cso.scot.nhs.uk)